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Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029560
Article Type:	Research
Date Submitted by the Author:	05-Feb-2019
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Keywords:	Depression & mood disorders < PSYCHIATRY, QUALITATIVE RESEARCH, REHABILITATION MEDICINE, Coronary heart disease < CARDIOLOGY, Ischaemic heart disease < CARDIOLOGY, Myocardial infarction < CARDIOLOGY

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Understanding men's psychological reactions and experience following a cardiac event: A qualitative study from the MindTheHeart Project

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- Word count (6356 words), excluding title page, abstract, references, figures and tables.

## Abstract:

**Objectives:** Depression, anxiety, and post-traumatic stress disorder (PTSD) are common following a cardiac event. Despite their high prevalence, these psychological disorders often go undiagnosed. Research suggests that men are particulary at higher risk and a better understanding of their experience with the cardiac event and the health services is key for adapting approaches to their needs. The aim of this study was to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment. **Design** Qualitative study (focus groups and semi-structured interviews) using interpretive phenomenal analysis. **Setting** Three Canadian provinces. **Participants** A total of 93 men participated in the study through focus groups (22) and semi-structured interviews (5). **Results** Four major themes emerged: 1) Managing uncertainty and adversity; 2) Distancing, normalizing, and accepting; 3) Conformity to traditional masculine norms; and 4) Social, literacy and communication challenges.

**Conclusions** Health professionals caring for men following a cardiac event must be aware of the psychological and social adjustments that accompany the physical challenges. However, there are a lack of explicit guidelines, tools and clinical training in men-sensitive approaches. Further research is required to better inform clinical practices and healthcare services.

#### Strengths and limitations of this study

Identified a new concept, the "broken masculinity" sheding light on an unrecognized aspect of the psychological reactions and help-seeking behaviour in men following a cardiac event.

Explored mens' experience following a cardiac event to inform the development of a mensensitive stepped-care model.

Men from cultural minority and Indigenous population were not included in this study. Thus, our results do not capture their needs and expectations. Further research is needed.

#### 1. Introduction

Depression, anxiety, and post-traumatic stress disorder (PTSD) are common among patients who experienced a major cardiovascular event (i.e. acute coronary syndrome (ACS)) [1]. Despite their high prevalence, these psychological disorders often go undiagnosed and contribute to an increased risk of related morbidity and mortality, as well as social and economic vulnerability [2]. Psychocardiology, or clinical psychology in the cardiac setting, is the science and practice of applying psychological knowledge to the prevention, treatment, and rehabilitation of patients with cardiac disease [3]. From this perspective, psychological and cardiac issues are interdependently addressed by collaborative interprofessional teams through patient-centred approaches.

Stepped-care models include a continuum of mental health interventions and services required to provide adequate health services and support in the most cost-efficient manner, based on patients' needs and choices. These models have shown effectiveness with different health conditions, including cardiac illnesses [4–7]. However, the last two decades of research in psychocardiology show that fewer than 25% of men with ACS engage in secondary prevention delivered by cardiac rehabilitation centers, seek support, or use appropriate timely interventions for their psychological distress and mental health [8–10]. Implementing effective psychocardiology stepped-care services for this population would require taking into account the social and behavioural determinants of men's health. To our knowledge, no research has been conducted on the acceptability and feasibility of a stepped-care model approach to psychological treatment that has been specifically designed to be sensitive to the needs and expectations of men with cardiac disease.

The MindTheHeart program, an innovative psychocardiology intiative launched in three Canadian provinces, aims to improve the prevention, early detection, and treatment of depression, anxiety and PTSD (D/A/PTSD) in men following a cardiac event. The cornerstone of this program was to design and test the feasibility and acceptability of a stepped-care approach to treatment structured into: Step 1: Psychoeducational intervention, Step 2: Group therapy including sessions with a significant other, and Step 3: Individual or couple therapy based on patient preference.

To appropriately design and tailor this stepped-care model to the needs of men following a cardiac event, it was essential to gain a better understanding of their experiences with heart disease and existing health services (or lack thereof). For the purposes of this article, our aims are to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment.

#### 2. Methods

#### 2.1. Study design

A qualitative study was conducted using an inductive phenomenological qualitative approach to provide a detailed description of the experience of men with cardiac disease while staying true to the collected qualitative data [11,12]. The consolidated criteria for reporting qualitative research (COREQ) were used to structure this study and ensure its methodoligical quality [13].

#### 2.2. Participants

Convenience samples were recruited through cardiac rehabilitation programs and cardiac departments or clinics at teaching hospitals as well as in the community in New Brunswick, Ontario and Quebec. To recruit participants we used a combination of active strategies (patients' solicitation at participating cardiac rehabilitation programs and a snowball technique) and passive strategies (radio broadcasts and local newspapers advertisement). The inclusion criteria were: 1) to be 19 and over in New-Brunswick, and 18 and over in Ontario and Quebec; 2) to have had a myocardial infarction, unstable angina, or heart surgery in the last 5 years with or without depression, anxiety or PTSD; 3) to be able to read and speak English or French; and 4) to be willing to participate in a group discussion. A sampling frame was developed to capture variation in age, marital status, cardiac health, mental health conditions, sexual orientation, spoken language (French or English), and socioeconomic status.

#### 2.3. Data collection

Data collection took place between May 2016 and August 2017. The focus group qualitative technique was selected to gather information [12]. This technique is appropriate for exploring patients' experiences and perspectives through a collective discussion. Interactions and discussions between participants are encouraged. Experiences and opinions are shared and explored while participants are questioning or challenging one another or disagreeing with one another. Initially, only focus groups were planned, but due to challenges in recruiting a sufficient number of partipants (time constraints, limited availability due to summer vacations, reticence to partake in a group discussion), we also carried out a total of five (n=5) one-on-one semi-structured interviews to ensure inclusiveness. Focus group discussions were facilitated by two members of the research team using a discussion guide (See Appendix 1). A preliminary version of the guide was reviewed by four male patients (two French and two English) to assess its intelligibility and appropriatness. All authors conducted the focus group or the semi-structured interview. The same interview guide was used for the semi-structured interviews, which were conducted either face-to-face or by telephone. Participants were aware of the study's aims and objectives. They had the opportunity to ask their questions to the interviewers prior to giving their written informed consent to participate. Focus groups and semi-structured interviews were conducted in English or French based on participants' preference and took place at the hospital or the university. Data collection continued until information and conceptual saturation.

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#### 2.4. Data analysis

The audio-taped focus groups and semi-structured interviews from the three provinces were transcribed verbatim and anonymized. When available, the field notes taken by interviewees were included in the analysis. An interpretative phenomenological analysis (IPA) was used to guide the thematic analysis of the data [14,15]. IPA is an inductive qualitative content analysis that allows for the description of patterns without *a priori* theories or models to guide the analysis. The aim of IPA is to explore in depth the participants' personal experiences, their meaning for them, how they make sense of these experiences, and what they would recommend to better meet their needs. The analytic approach followed iterations of thematic content analysis and codes were created through open and axial coding to capture emergent themes [16].

To effectively manage the amount of collected data, we organized a collaborative analytic team. The first author was responsible for the data analysis management process including the development of the MindTheHeart manual for the qualitative study, the delivery of data analysis training sessions and the development of a codebook. She acted as a referee when needed. To ensure consistency in data analysis, 10% of the transcribed verbatims were randomly selected and four analysts independently coded 10% of the material. This strategy allowed the calculation of the inter-coder reliability [17]. The intercoder reliability check consisted of coding and comparing the findings of each of the coders (2X2). The Cohen coefficient was used to assess to what extent the data deviated from perfect reliability. A coefficient of 80% or more was considered appropriate. Once this was reached, we considered that all analysts were using the same interpretative approach and data were analysed in a complementary manner. We performed three rounds of inter-coder reliability tests and two rounds of data analysis training sessions to create a convergent analytic approach. The transcribed material was analyzed through a systematized analytic process under the shared server of Nvivo11-Pro (QSR International, Doncaster, Victoria, Australia).

Patient and Public Involvement: Patients were not involved in the design of this study. Results were presented through public talks.

#### 3. Results

We carried out a total of 22 focus groups (88 men) and 5 semi structured interviews with 5 men. In total, 93 men participated across the three provinces. Each focus group consisted of three to six participants and lasted approximately two hours (+/- 35 minutes). The semi-structured interview lasted between 60 and 90 minutes. The sociodemographic characteristics of the partipants are presented in Table 1.

#### Table 1 Sociodemographic characteristics of participants

	Mean age (years) (SD)	Ethnicity	Education	Marital status	Employment status	Language		
New Brunsw	New Brunswick							
Focus groups – (8 groups for a total of 37 men)	64.2 (+/- 9.7)	Caucasian: 37	Secondary: 17 College: 4 University: 16	Single: 3 Married: 25 Divorced: 2 Common law: 4 Widowed: 2 Widow + Divorced: 1	Employed: 13 Retired: 18 Sick leave: 3 Employed + retired: 1 Semi-Retired: 2	6 EN 2 FR		
Semi- structured interviews (4 men)	51.5 (+/- 4.8)	Caucasian: 4	College: 3 Secondary: 1	Single: 2 Married: 2	Employed: 3 Sick leave: 1	3 EN 1 FR		
Ontario	1					1		
Focus groups - (9 group for a total of 36 men)	65.8 (+/- 15.5)	Caucasian: 34 Caucasian + Jewish: 1 Caucasian + First nation: 1	Primary: 3 Secondary: 2 College: 7 University: 24	Married: 19 Separated: 2 Divorced: 7 Common law: 7 Single: 1	Retired: 28 Sick leave: 3 Retired: 27 Employed + retired: 12	4 EN 5 FR		
Quebec								
Focus groups - (5 groups for a total of 15 men)	67.5 (+/- 8.9)	Caucasian: 15	Primary: 2 Secondary: 4 College: 4 University: 5	Married: 9 Common law: 4 Single: 2	Employed: 1 Retired: 12 Sick leave: 1 Unemployed: 1	4 FR 1 EN		
Semi- structured interview (1 man)	Not inclue	led to protect fo	or anonymity a	nd confidenti	ality			

EN: English; FR: French

Interpretive phenomenological analysis of the gathered qualitative data from the three provinces highlighted the emotional issues faced by men and the patterns of psychosocial

adjustment challenges in men following a cardiac event. Emerging themes were categorized and presented bellow. Quotes have been reproduced to illustrate key points. To preserve anonymity and confidentiality quotes were tagged using a pseudo (male name). French quotes were translated into English for the purpose of this publication.

#### 3.1. Managing uncertainty and adversity

A temporal sequence emerged across data as being instrumental in affecting men's experience following a cardiac event.

#### "Not me, not now!" Denial reaction and delay in seeking help

Refusing to recognize the cardiac event and purposely delaying the hospital (emergency department) visit seems to be a prevailing behaviour among men. "I was working, my back got very sore, and I broke out in a cold sweat, but I finished my shift. I knew it was a heart... it was my heart. So, I went home, showered, ate a little bit and had my last cigarette, cause I'm a smoker." - **Gérard.** "I rolled over in the bed a couple of times when I should've gone to the hospital. Cause I know my wife would freak out, she'd be worried about me, right? And I know I'd be in the hospital for 12 hours, which would mean I couldn't go to work the next day. So I'm just going to roll over and just, you know, roll the dice on this, on this event, today, and see how it goes." – **Tim**. "I was home with chest pains. Not pain, but just pressure in my chest. Never for a minute, for a second, it clued in that I had a heart problem. On Thursday. I went back to work on Friday. Same pain, but when I sat down and rested, it went away. On Saturday I was home. I started my power saw to cut branches on trees and cut down a tree, and clean up the yard. And I only went to the doctor on Tuesday of the following week. Expecting to go there and he would say "Take a few tests and you'll go back home and we'll call you in a few weeks". Well, it changed. When he said "You're not going anywhere. You're going to be here a few days". And I realised I was stupid. I should've gone on Thursday." – Gary

Across discussions, two contrasting explanations for the denial reaction and delay in seeking help emerged: 1) the sense of invincibility perceived by younger men (30 to 50 years old) as they did not see themselves at risk and could not understand/accept why they suffered a cardiac event: "younger men are brought up to feel that they are a bit invincible, that you know, they're bullet proof and you know that doesn't happen to them" - Paul, as well as by older men who had previously recovered from a severe illnesses such as a heart attack or a cancer and perceived themselves as warriors, "I survived a cancer before, I haven't much of a fear of dying"-Pat and 2) the sense of vulnerability expressed by men who described the cardiac event as a loss (of control, of power, of dignity and of autonomy) or a fear (of receiving a life-treathening diagnosis, of permanent incapacity/disability, of early retirement or of death). An additional explanation mentioned across groups, was the competing priorities of daily living and putting others above self " it's hard to take time for yourself when you have a lot of obligations"- Marc. Stressing on lack of time and being busy is used to positively explain and justify the treatment-seeking delay behaviour. This type of avoidance behaviour in regards to seeking help was often perceived as being somewhat of a responsible and altruistic

behavior, thus making it more acceptable and meaningful and reinforcing the masculine gender role and its impact on engaging in help-seeking and treatment-seeking.

# "What am I doing here? What'd be my life once I'm back home?": The in-hospital journey

The in-hospital stay, whose length varied according to the severity of the cardiac event, was most often described as very difficult, involving sleepless nights, worries, fear of death, and sometimes anger. Having to "stay in bed" was depicted as a failure, a loss of power and confidence, or an unfair situation. "It changed my life totally. Like, you know, I was pretty confident, pretty, you know, I was a supervisor at my work, captain of my team, just, you know, that 10 feet tall and bulletproof. I wasn't there anymore, right?"-Jacques While reactions varied, one particular question transcended across groups: "what would be my life once at home?". The anxiety generated by this question was discussed in groups as an important concern.

Across groups, men typically shared that they were very satisfied with the care they received (i.e., procedures, medications, interactions with health professionals about their cardiac condition) during their hospital stay, but that one thing they tended to avoid discussing openly was their apprehension about life after hospitalization. Thus, uncertainty about life after hospitalization emerged as a dominant theme across groups when discussing in-hospital challenges. In-hospital uncertainty was further characterized by lack of, or inability to achieve a clear understanding about the cardiac event, its impact on the body and daily functioning, eventual impact on one's job or employability, and risks in terms of survival (fear of death). The main reasons why men experienced anxiety in the form of uncertainty about the future were that they (a) did not understand, or accept, the cardiac event; (b) did not feel in control of their future (how things are going to evolve?); (c) were intimidated by unintelligible medical terminology and high-tech procedures; and (d) apprehended the adjustements and the changes to be implemented once at home. Uncertainty about the future was associated with lack of self-confidence and was exacerbated by poor health communication on the part of professionals and in some cases the patients themselves, who were often reticent to share their concerns or to ask questions. Communication behaviours on the part of health care providers such as speaking in general terms and referring to population statistics (as opposed to using more precise and personalized information), only communicating via short conversations in a shared room while the patients were in bed (as opposed to creating opportunities for asking questions in a more confidential environment), or providing unclear explanations using medical jargon (as opposed to clear explanations in lay terms), appear to play a critical role in generating and exacerbating feelings of uncertainty and apprehension about the future.

#### "I'm not the man I used to be!": Post-hospital discharge

Returning home following a cardiac event was discussed as an important transitioning phase. Group discussions revealed that being told to "*slow down and stay home,*" even

for a short period, was often experienced as unacceptable and devaluing. Post-hospital discharge, especially in the early going, was associated with psychological distress, frustration, and discomfort related to adopting the recommended lifestyle changes (e.g., lower sodium intake, eating more fruits and vegetables, quitting smoking), resting at home, and daily medication intake. Lack of undertanding of medical advice and recommendations, lack of preparedness for the changes to be implemented, and the experience of having had a "brush with death" were mentioned as major stressors.

"You know, the thing that stuck in my mind the most, of this whole episode... I talked to the surgeon before the operation, and he went through all the steps of what's happening, and bottom line, there's a 2% chance that you're gonna die... That gets your attention"-Henry. "Like, this gentleman keeps saying "If it's your time to go, it's your time to go." But for me, I'm not saying that I'm more or less important, but I have a young kid, so when your doctor tells you that you better make sure that your will is fully done and your financial situation is good cause you're a ticking time bomb, at 40, I have a young kid and for me, it plays a lot in my head, right"-George. "What I found the hardest of all is before my operation and after, they told me what I could do, what I couldn't" -Virgile

Perceived control was identified as a dynamic cognitive process that fluctuated in response to the cardiac event. Men constantly attempted to retain or gain control during the rehabilitation phase and even beyond this period. Changes in environmental circumstances, such as being hospitalized for extended periods of time, re-hospitalization for complications and then being discharged home, impinged directly on their ability to feel in control of their daily lives. The process of gaining a better sense of control was facilitated by rationalizing, or making sense of a new phase in their treatment or illness prognosis or by gaining awareness of environmental challenges "once you accept that you are restricted in your physical abilities it gets easier"- Paul.

The post-hospital discharge and recovery process experience are mainly shaped by age, social connectedness (life partner, family, friends, and community involvement), psychological preparedness, personality, and economic status (finances, employment, etc.). Groups' narratives revealed that feelings of powerlessness and sleep disturbances were experienced at all stages of the rehabilitation process and were often associated with the fear of dying. *"I was afraid for a long time to go to sleep. I would stay up for like three days until somebody slept with me more or less, right? My girlfriend at the time, we didn't stay together every night, but if she wasn't with me, I wouldn't sleep. I was afraid to go to sleep and not wake up."-Albert.* 

#### 3.2. Distancing, normalizing, and accepting

Men reported that stepping back and reflecting on their own emotional reactions and experiences helped them making sense of their changing lives post-cardiac event. Two perpectives emerged : experiencing it as a personal failure and/or as an opportunity (a second chance for a better life). In both perspectives, they were ready to accept this new normality and were ready for adjustment. *"Once you accept that you are restricted in your* 

physical abilities it gets easier"-Bernard. They reported using various strategies (spirituality, religion, faith, praying, introspection, meditation) as means to help them make sense of their cardiac event and accept the situation "Well, I wouldn't say I was completely free of worry for myself. Like the day before surgery, I went up to Sainte-Anne-De-Beaupré and I went to confession. So I was, you know. I wasn't completely fearless, going in"-Paul. "Well you know there's a lot of factors that impact on getting better support, prayer... I think prayer is a big thing, faith is a big thing too, you need to go for help"-Jack. "Spirituality helps, it gives you strenghts and courage. I think it's a psychological thing"-Marc.

Increased awareness of one's mortality was described as a motivating factor to help them prioritize taking charge of their health. Redefining priorities with their life partner and family, or engaging in companionship was also described as helpful "My wife as well was very helpful, which means, she was not entirely too sympathetic which is, this is what you need to do, you know (laughs)."-Patrick "Like she took care of all my meds. Prior to the surgery, she wouldn't even know what meds I was on. But after that, she was the one who knew what med, and when there were changes"- Albert.

After being stabilized medically, reactions varied among men. Groups discussed three main reactions: (a) processing and reflecting on the lived experience and engaging in adopting a healthy lifestyle as a personal or familial challenge, (b) taking the necessary time to process the traumatic event (to absorb the shock and understand what was happening) and then gradually exploring options and implementing changes, and (c) resisting and ignoring recommendations, using self-reliance and continuing the same lifestyle as before the cardiac event. *"I disregarded anything that my doctors were telling me, and I said that I had to take control of my own situation."*-Charles

#### 3.3. Conformity to traditional masculine norms

Dominant masculine norms can affect perceptions, acceptance, and normalization of the psychological distress following a cardiac event as well as help-seeking behaviours and mental health services utilization. The "broken masculinity or the phallic devaluation" emerged as a transversal theme illustrating how deeply "masculinity and virility" were affected following a cardiac event. The functional limitations (i.e. staying at home, not driving, not shovelling snow, not lifting heavy weights), prescribed by their doctor or that were consequences of their heart condition (i.e. erectile dysfunction), were experienced as a major loss of manhood "Well, weakness also. There's a role. You're the father, and there's a role. And there's responsibilities that go with that role. And you want to continue to do your job, as a father. And you don't want to show them that you're as vulnerable as you are at the moment. You kind of try to carry through. Which is tiring, cause then when they're gone, you're just wiped out. You just put everything. You put the whole day's energy into that session with them." – Jean-Pierre. Perceiving their social role as "family breadwinner" or "family strong pillar" prevented men from sharing their emotions and worries to their children or relatives. The altruistic behviors, such as protecting relatives from worries, are valued by men and are used as intrinsic strategies to regain selfconfidence and sens of manhood. "Well, I have a 14 year old son, who looks up to me

 I'm sure. I'm his father. So, you know, sometimes when I'd see him, surely, I'd say after the surgery when you're really not feeling yourself... You have to put on a game face because you really don't want to show exactly how you feel to your children, cause they're going to worry." - **Brian.** 

The tendency to view and label certain behaviours as "feminine" as opposed to "masculine" seems to be an aggravating factor in terms of delaying or avoiding seeking help and using mental health services "...women will tend much more to talk about it to their friends in regards to how they're feeling. Where a man, sometimes it's hard to share with your partner sometimes. You don't want to show that sign of weakness, and that's the way that I look at it." – **Bill** "Suddenly you go through a heat attack and you will be like that (clic) the man they expect you to be, I mean the open minded... the touchy feel... you know... talking about private things... with people you don't know, Oh wow! Not me..."-**Greg** "I find that women will talk to each other about emotions and how they feel. But how often do you go to work and sit down with one of your friends and start talking about your emotional problems? Not often. It's just something that men don't do"-**Alban** 

Men working in male-dominated workplaces (i.e., paramedics, police, military, construction, fishery industry) stressed the importance of educating people in their workplaces and of providing them with supportive tools and strategies. "*The other thing too is like, in the military, I was trained for 32 years to be macho. There's no such thing as being depressed or tired or... you know what I mean? You'd just go out and do your thing, that's just the way it was. And that training, today, is still instilled in me."*- Martin.

#### 3.4. Social, literacy, and communication challenges

Following a cardiac event, men had to change the patterns of their lives and adjust to changes in their role as life partners, parents, and employees. There was a perception of loss of confidence in their physical capabilities and functioning in family and work relationships. Low social connectedness and support before the cardiac event was discussed in groups as a risk factor for cardiac disease and mental illeness and associated with poor mental functioning and quality of life during the recovery period. The quality and the intensity of the familial relationships as well as friends and co-workers relationships vary over the course of recovery from the cardiac event and are dependent on men's acceptance of the situation and for help. Following a cardiac event, men had to change the patterns of their lives and to adjust to different changes in their role as life partners, parents and employees. The perceived loss of confidence in their bodily capabilities and functioning affecte their family, friend and work relationships. When discussing about social support and its relevance for a healthy recovery, the necessary balance between the expected and the received support emerged as key. Indeed, while they found it sometimes difficult to share their thoughts and challenges with their relatives, men appreciated the attention, the compassion, the understanding and the support of their life partner, family members and friends. Supportive interpersonal relationships were viewed as helpful for breaking the cycle of distress and anxiety. The support received improved men's trust in their ability to deal with the cardiac event, the

cardiac rehabilitation and the necessary adjustments. However, men mentioned being irritated because of the overprotectiveness of their relatives. In particular, being under 'spouse's management', they felt that they had lost part of their personal space, their independence and manhood. '. ...All of a sudden, people feel, my wife in particular, well, here's somebody who's not an invalid, but we have to, you know, every time you do anything it's well, you shouldn't be doing this, you shouldn't be doing that, you shouldn't be... And that sort of affected me – it still does – more than any other things...' – Mark.

Sexual problems developed in the aftermath of the cardiac event, either functional ones related to their ability to sustain an erection or to ejaculate (often side-effects of medications), or psychological ones that involved fears of exacerbating their heart condition if they were to engage in sexual activity were described as a major concern. "Sexually, I'm not the man I used to be. It's just – and I blame it on the pills – it's just that my life has changed drastically...I keep toying with the idea that maybe I should stop taking the pills, but I know that it's gonna get me one way or the other... So... it's really finding a sweet spot with the right medication."-Wayne "you don't have anymore the sexual drive, you know, that you had before"-Martin

#### **Concerns about work**

As work is a significant aspect of personal and social identity, being on a long term sick leave may lead to feeling of shame and guilt or regarded as incompetent, incapable or physically weak. "I've been out of work for a year and a half. I don't want to go back there. I don't want the stress of it. In the meantime, my work's moving, so we're all going to lose our jobs anyways. I've been there 22 years. So it's just another stressor, right? And a lot of stuff outside of work, and it's a helpless feeling."-Paul. "I supervised like the Giant Tiger warehouse. I couldn't do that anymore. You know what I mean? Stuff like that, you know? The only thing I do anymore is play baseball. That's just it..."-Richard. Early returning to work, even againt medical advice, is discussed as a problem-solving strategy to reinforce self-confidence and overcome stress. "The cardiologist came, he says, "well, we have to do a triple bypass". I looked at him, I said, "well, how long am gonna have to stay in the hospital?". He said, "two weeks". I says, "I don't have time for that. I have to be back at work for the 29th"-Serge "after my heart attack, the only thing I wanted to do was get better so I could go back to work, 'cause I'm only 52 and I need to work. So, that's all about"-Georges

### Health literacy, health communication and health services navigation

Men's health literacy was pointed out as a major challenge. The lack of understanding of the medical jargon and procedures emerged as an additional stressor and was described as a barrier for asking questions and seeking for more information, explanations, or advice. The bidirectional association between cardiac health and mental health was unclear and not fully understood. Moreover, the mental illness signs, symptoms and diagnostic labels seem to interfere with the masculine ideals. Indeed, men did not identify themselves as "depressed", "stressed" or "anxious" but used restrictive vocabulary to

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express emotional distress like "low energy", "challenged" or "meeting temporary difficulties".

Men valued the quality and human kindness associated with health services they had access to and described how the interactions, the conversations and the alliance they had with their healthcare providers enhanced their compliance with treatment plans and improved their general mental and physical health status. "...They gave me all the paperwork, all the stress things, charts and stuff, and my GP was great. She would ask me how my mental state was. I don't know guys like that. I appreciate it, but my doctors know her when I go in her office. She's in no hurry. If I'm sitting there crying for 15 minutes, she's there for 20 with me. So, yeah, I'm very lucky. I have great doctors..."- Serge Men put a strong emphasis on the quality of the communication they had with the health professionals, such as being listened to, not being rushed, receiving care with sympathetic attitude, being trusted and taken seriously "I feel comfort. I feel comforting going to them. I really get a sense of my doctors that they really care about me."-William.

However, the lack of time allocated by physicians for talking about emotional distress and social challenges following the cardiac event was reported as a barrier for access to supportive and caring services "You look at the doctor as being event-centered. In other words, he's there for a medical purpose. You have your 10 or your 15 minutes, and you're gone. You know, we're talking today about emotions, and this seems to be a timeconsuming expensive exercise that at least the professionals I've dealt with haven't been available for. And you feel as though you're intruding on their importance, I guess, by, you know, having long chats and that sort of thing."-Patrick. Men felt pressured by time "I just felt like I was just in and out like I was at a hair salon or something. You know, get this done, get the ECG done, and okay, see you later. Here's a prescription... I always felt like I was being rushed and brushed off. And so there was no relationship"-Mike. "You know, you've got your so many minutes. And I still think in our health system – and maybe not what's in the future – but if there was some minor pay for service, I think that would be helpful because you always feel you're on a sort of a diet of service. You're in; you're out, and of necessity. They move on to the next person."-Bruce.

The lack of knowledge about the health system and how to navigate services and manage medical information making the health system perceived as a "*men-unfriendly space*" where they feel uncomfort and uncertainty "*I think there's a problem with men as a whole, and you know, women seem so much more in tune with, you know, going to see the doctor for themselves, child birth, kids, I mean, when my son was ill, I never went to the doctor with him, my wife took him and it just wasn't a place I'd go; didn't know him very well, didn't know much about what to tell him"-Philip. Moreover, the perceived conflicting information received from different health professionals increased anxiety and stress on how to manange health condition and how to use health services. Men participating in cardiac rehabilitation programs reported the benefits of social interaction with cardiac fellows, identified as the "cardiac family", sharing similar health condition that helps normalizing the challenges and accepting the "new reality".* 

#### 4. Discussion

This study aimed to describe the emotional issues and patterns of psychosocial adjustment experienced by men following a cardiac event. Across the three provinces, participants showed homogeneity in reported experiences of the cardiac event, and its subsequent psychological reaction and social impact. Adaptation to the event, both psychologically and socially, did not appear to relate to the geographical location but varied by severity of the initial event, socioeconomic status, age and cultural norms and believes. In the focus groups men opened up readily about their emotions and their vulnerabilities. They shared their experiences of difficulties in adapting and adjusting to their "new post-cardiac identity" and the need to accept new roles. They acknowledged that this adjustment needed to be worked out with their environment, their home, their family, their friends, and their workplace. Most often they found support through their partners and through peer support when they attended cardiac rehabilitation sessions. The focus groups sessions helped to validate and normalize their initial reactions. They regretted that the health professionals they had encountered had not enquired in a systematic way about their mental well-being as they would about their physical symptoms or diet or exercice. One important overarching element that was brought forth by men was the lack of systematic attention given by health care professionals to the psychological consequences of having experienced a cardiac event. It was suggested that some professionals may bring up the subject, but in most instances, the question was not asked. Therefore, there seems to be a lack of consistency within the health system in regards to the attention paid to the psychological sequelae of heart disease. These aspects were reported in previous studies on various health conditions [18–20]. However, there still a lack of clear and evidence-based guidelines and resources to support mensensitive health communication as well as clinical practices to foster men's mental health. This study also revealed how traditional masculine norms can affect the way men experience and seek help for emotional distress following a cardiac event, and how these behaviour affect their halth and wellbeing. Tailoring and targeting clinical interventions may increase men's service uptake and the efficacy of treatments. Specific factors associated with men's access to, and engagement with mental health care are critical to increasing help-seeking, treatment uptake, and effectual self-management among men experiencing emotional distress following a cardiac event.

While the literature contains extensive reports on "toxic masculinity" as a major determinant of men's health [21] or its impact on help-seeking in men [22], our study revealed "broken masculinity" to be an untold and unrecognized distress following a cardiac event. We found that men experienced a great deal of psychological anguish over the changes imposed by their cardiac illness, and that these changes were directly related to their sense of themselves as men in their family and in society. Our results confrm, as suggested by previous research, that it will be crucial to address these concerns in a systematic way in order to combat symptoms of depression, anxiety, and post-traumatic stress in men following a cardiac event [23,24].

#### Limitations

Our sample was limited but we reached information and conceptual saturation. Our participants were mostly in their sixties and over, which is representative of the population of men with cardiac disease. However, it would be of interest to study more specifically cardiac disease in men in their 30s, 40s or 50s as these population is growing among cardiac men.

The participants in our study were essentially white, with little or no representation of other ethnic groups nor indigenous poeple. This may not be representative of larger urban Canadian settings.

Although our inclusion criteria indicated a cardiac event in the last 5 years, for some participants, the first event may have occurred some 10 years prior and there may have been changes in cardiac rehabilitation programs and health services. Moreover, the responsiveness of health professionals at the time may have been different. A quantitative study exploring these aspects may allow to retrieve accurate information.

#### Strengths

This study is the first of its kind to delve into the subjective experience of men with heart disease and to examine the link between their reactions to their cardiac event and their mental health. We were able to detect key themes that are likely to resonate with most men who have heart disease, which could serve as a foundation for the development of intervention programs, i.e. the stepped-care model.

#### 5. Conclusion

This paper highlights the significant emotions that arise following a cardiac event and how men attempt to counter them as best as they can. It is known that men have a tendency not to talk about their emotions or to express them differently than women do. Health professionals caring for men in these contexts must be aware of this and receive training in gender-sensitive approaches. It will be important to inform their patients of the possible occurrence of such emotions as well as the tools and ressources to self-manage as a first step. Considering the impact on morbidity and mortality when anxiety, depression, or post-traumatic stress are in the diagnostic picture, cardiologists, cardiac surgeons and family physicians as well as psychologist and other health professionals involved in cardiac rehabilitation programs must be ready to inquire systematically and to screen their patients for common mental health conditions. Improved mental health of these patients will most likely improve their cardiac disease. A larger study is underway to longitudinally investigate the need for emotional support among men following a cardiac event as well as exploring acceptability and feasibility of men-sensitive steppedcare models.

**Ethical approval** The study received ethical approval from the research ethics boards (REB) of the participating study sites: Réseau de santé horizon : 2016-2295; Réseau de

santé Vitalité : 2016-04-13; Université de Moncton : 1516-047; Hospital Montfort : JJ-04-11-15; Institut de recherche cardiologie d'Ottawa : 2014-1801 (#projet), formulaire F11-4318; Université de Montréal : MP-33-2016-2006 (# projet), demande # F0-7529; and Hôpital de Hull : 2016-159 (# projet). All participants signed a confidentiality and consent form.

Acknowledgements The authors would like to thank the staff of the participating cardiac rehabilitation programs for their support with men recruitment, and the research staff (Arielle Doiron, Lise Gallant, Sarah Nowlan, and Mireille Ntambwe) for their contribution in the transcription of verbatims, the data organization and the preliminary coding. The authors would also like to thank the men who have contributed to the focus groups and semi-structured interviews.

**Funding** This paper represents independent research, for which authors received funding from the Movember Foundation-Canada and from the New Brunswick Health Research Foundation. JJ would also like to acknowledge the logistic and financial support provided by the Centre de formation médicale du Nouveau-Brunswick to support this publication.

Competing interests None declared.

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#### **APPENDIX 1**

#### « MIND THE HEART » PROJECT

#### FOCUS GROUP DISCUSSION GUIDE

#### **ENGLISH VERSION**

#### INTRODUCTION

Thank you for agreeing to participate in this focus group discussion. This discussion is part of a multi-site participatory action research project, « MindTheHeart », funded by Movember Foundation Canada and the New Brunswick Health Research Foundation that aims at raising awareness for psychologically healthy workplaces for men living with or at risk of HD.

The purpose of this focus group is for the research team to understand the needs, expectations and preferences of men at risk of or living with HD, with regard to interventions such as mental health promotion, mental health prevention, and mental health interventions for MD/AD/TRD. The information gathered will help the research team to design interventions that meet the specific needs of men with HD to prevent or early detect and treat co-occurring mental health issues.

Before we start the discussion, allow us to clarify some points.

1. Could you all kindly verify that you have already signed the consent forms stating your voluntary participation in this focus group?

Yes 🗆

No 🗆

- 2. The duration of the focus group discussion will take 90 to 120 minutes in which you have the right to leave the group at any point in time.
- 3. The whole session will be audio recorded to ensure the accuracy of the information that you provide. However the consent forms that you have signed will ensure that all the information that you share today shall be confidential and anonymous.
- 4. Please note that each of you confirms that you are aware that anything said during the meeting has to be kept confidential and that you understand that you are not allowed to disclose any information or any names related to this focus group.

Would anyone like to ask any question or has any clarification related to this focus group before we start?

Before we start, could you please take a few minutes to complete this general information sheet? (Give them the information sheet below)

52				
53	Date:	 	 	 
54				

#### 

Page 2	21 of 25	BMJ Open
1 2	The ob inform	ojective of the following form is to collect general information about you. You can be assured that the ation collected will remain confidential and anonymous.
3 4	1-	Age
5 6 7	2-	City of residence
8 9 10 11 12 13 14	3-	Familial status (tick as apply).    Single (never married)    Married    Common law partner    Divorced    Widow
15		Other (specify):

4- Level of education: (tick as apply).

- Not schooled
- Primary
- Secondary
- College
  - University
  - Other (specify):\_
- 5- Employment status: (tick as apply).
  - Employed
  - Retired
  - Sick leave
  - 6- Preferred language for health services (tick all that applies).
    - French
    - English
    - Others (specify):
  - 7- What is your ethnicity? (tick all that applies).
    - White/Caucasien
    - Black (ex., Haitian, African, Jamaican, Somalia)
    - Latino/Hispanic
    - Asiatic (ex., Chinese, Japanese, Vietnamese)
    - Middle East
    - Native/First Nation/Mixed-Race
    - Pacific Island
  - Other (specify):

#### Health status

- 1- Are you suffering from, have you ever suffered from or are you at risk of heart disease? (if yes, please specify)
- 2- Are you suffering from a mental health issue? (if yes, please specify)

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# FOCUS GROUP DISCUSSION GUIDE

1	
2	A. Patient Experience
3	How would you describe your experience with the mental health issues that you have been experiencing following your
4	HD?
5	- Physical well-being (performing your daily activities, energy levels and physical activity)
6	- Emotional well-being (interest in sex, experienced feelings, mood and relationships with others)
7	- Mental health issues (mood and anxiety, ability to make 'good' decisions and be productive)
8	- Financial situation
9	Employment situation (absence from work productivity demotions arguments with colleagues and supervisors
10	- Employment situation (absence from work, productivity, demotions, arguments with concagues and supervisors,
11	Sugnia, ioss (auvaniages, respect, connuclee))
12	- For many men, self-reliance and being competitive are important characteristics. How about you? what are
13	important manly characteristics for you? How might that have changed with HD and mental health issues?
14	- How do you deal with those changes?
15	
16	B. Health Promotion and Prevention Needs
17	What do you know about the link between HD and mental health issues in men?
18	- Health literacy/Knowledge/Health education
19	- What do you wish you had known or done that might have helped you avoid HD and mental health issues?
20	- For other men experiencing HD and mental health issues what are the most important pieces of information about
20	the link between HD and mental health issues and how might they be best conveyed?
21	Regarding risk reduction for HD and mental health issues: What kind of information about mental health and HD do you
22	think will be most usaful for you?
23	Type of information (statistics, recommandations, health advice, explanations, )
24	- Type of information (statistics, recommendations, nearly advice, explanations)
25	- Communication channels: (read, audio or visual media, seminars, peer education, educational materials, others
20	specify)
27	- Location of information delivery (workplace, health care services, community, media)
20	- Timeliness of information delivery (moment/delay)
29	- Websites, apps, social media, men testimonies as a source of information, interest and use
20 21	
27	C. Health Services and Clinical Care
22 22	What is your experience with the health care that you were provided due to your HD and mental health issues needs in the
27	last five years?
25	- How connected are you to the health care system and specialist heart and mental health services?
26	- Relevance of care: Many men tell us they don't want to rely on medications to ensure their mental health or treat
30 27	specific ailments such as depression? What is your perspective/experience? What is your advice to health care
27 20	providers about working with male nations who have experienced HD and/or mental health issue?
20	- Utilization of services: Lots of men are reticent to use professional mental health services – why might that he?
40	What about you, what challenges did you have in seeking heart or mental health care?
40	Availability and access to care? (avistance of men sensitive services, factors related to utilization of services:
41	- Availability and access to care? (existence of men-sensitive services, factors related to utilization of services.
4Z 42	What were some of the group that you guagest he improved? (your sympositions)
45	- what were some of the areas that you suggest be improved? (your expectations)
44 45	Could you please describe your experience with your health care professional (family doctor, cardiologist, nutritionist,
45	kinesiologist, social worker, psychologist, and counselor) regarding information about mental health issues and heart
40	disease?
47	- Information/Education provided: What type of patient are you? One who likes to be told what to do or would you
48	rather be more involved in the decision making and strategies? Please provide an example of that round your HD
49	and/or mental health issues?
50	- Perceived expectations and needs
51	- Patient/Clinicians dynamics (communication, relationship, openness, empathy and shared-decision making)
52	- Proposed improvements: Can you provide an example of a positive interaction/relationship with a specific health
53	care professional? What are the characteristics of a great health care professional?
54	- How does the gender of the health care professional influence that relationship?
33 56	- Some men like to lead – others like clear instructions. What is your preference and experience of interacting with
20 57	health care professional?
5/ 50	nourai ouro prorossionar:
20	3
59 60	For peer review only - http://bmiopen.hmi.com/site/about/quidelines.yhtml
00	ror peer review only intep.// onlypen.only.com/site/about/guidelines.xittin

# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

#### Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

# YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1. Inter viewer/facilitator	All authors conducted the focus group or the semi-structured interview	Method- Page4	
2. Credentials JJ PhD, MD JG PhD, CPsych MHC MSc, MD FT PhD, LPsych HT CPsych BD'A PhD PSG PhD, CPsych		Title page-1	
3. Occupation	What was their occupation at the time of the study? Researchers, Clinicians or both.	-	
4. Gender	Was the researcher male or female? Males (JG, PSG) and Females (JJ, MHC, FT, HT, BD'A)	-	
5. Experience and training	What experience or training did the researcher have? A MindTheHeart manual for the qualitative study was developed. Training was offered to the researchers and the research staff involved in this study.	Methods-Page 5	
Relationship with participants			
6. Relationship established	Was a relationship established prior to study commencement? No	-	
7. Participant knowledge of the interviewer	What did the participants know about the researcher? Ethical approval had been granted from REB in all participating sites.	Ethical approval- Page 15-16	
	information sheet and had the opportunity to ask their questions to the interviewers prior to giving their written informed consent.	Method-Page4	

8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias,	-
	research topic	
	No interviewer-related bias was identified.	
Domain 2: study design		
I neoretical framework	What mathedalagical griantation was	Mathada Daga 5
orientation and Theory	stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis Open and axial coding with interpretative phenomenological analysis.	Methods-Page 5
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball Convenience samples The inclusion criteria were: 1) to be 19 and over in New-Brunswick, and 18 and over in Ontario and Quebec; 2) to have had a myocardial infarction, unstable angina, or	Methods-Page 4
	heart surgery in the last 5 years with or without depression, anxiety or PTSD; 3) to be able to read and speak English or French; and 4) to be willing to participate in a group discussion.	
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email To recruit participants we used a combination of active strategies (patients' solicitation at participating cardiac rehabilitation programs and a snowball technique) and passive strategies (radio broadcasts and local newspapers advertisement).	Methods-Page 4
12. Sample size	How many participants were in the study? 93 men	Results-Page 5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	-
Setting		
collection	vvnere was the data collected? e.g. home, clinic, workplace At the University or the hospital	Methods-Page 4
15. Presence of non- participants	Was anyone else present besides the participants and researchers? No	-
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date Data presented in a Table (Table 1)	Results-Page 6

Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Yes	Appendix1 Guide
	Was it pilot tested? The guide was reviewed by four patients who did not participate to the study.	Method-Page 4
18. Repeat interviews	Were repeat inter views carried out? If yes, how many? No	-
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Audio	Methods-Page 4
20. Field notes	Were field notes made during and/or after the inter view or focus group? Yes	Methods-Page 5
21. Duration	What was the duration of the inter views or focus group? Each focus group consisted of three to six participants and lasted approximately two hours (+/- 35 minutes). The semi-structured interview lasted between 60 and 90 minutes.	Results-Page 5
22. Data saturation	Was data saturation discussed?	Methods-Page 4
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? No	-
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data? 12 coders	Methods-Page 5
25. Description of the coding tree	Did authors provide a description of the coding tree? No	-
26. Derivation of themes	Were themes identified in advance or derived from the data? Derived from the data	Methods-Page 5
27. Software	What software, if applicable, was used to manage the data?	NVivo 11 Pro
28. Participant checking	Did participants provide feedback on the findings? Yes	Strengths and limitations
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number Yes	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings? Yes, mainly	Discussion
31. Clarity of major themes	Were major themes clearly presented in the findings? Yes	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? Yes	Discussion

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#### Understanding men's psychological reactions and experience following a cardiac event: A qualitative study from the MindTheHeart Project

Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029560.R1
Article Type:	Original research
Date Submitted by the Author:	21-Aug-2019
Complete List of Authors:	Jbilou, Jalila; Universite de Moncton, Psychology; Universite de Moncton, Centre de formation médicale du Nouveau Brunswick Grenier, Jean; Hopital Montfort, Institut du Savoir Montfort Chomienne, Marie-Helene; University of Ottawa, Family Medicine; University of Ottawa, School of Epidemiology and Public Health Talbot, France; Universite de Moncton, Psychology Tulloch, Heather; University of Ottawa, University of Ottawa Heart Institute, Cardiac Prevention and Rehabilitation D'Antono, Bianca; Universite de Montreal, Psychology Department and Research Centre at the Montreal Heart Institute Greenman, Paul; Universite du Quebec en Outaouais, Département de Psychoéducation et de Psychologie; Hopital Montfort, Institut du Savoir Montfort
<b>Primary Subject Heading</b> :	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	Depression & mood disorders < PSYCHIATRY, QUALITATIVE RESEARCH, REHABILITATION MEDICINE, Coronary heart disease < CARDIOLOGY, Ischaemic heart disease < CARDIOLOGY, Myocardial infarction < CARDIOLOGY
	·

# SCHOLARONE<sup>™</sup> Manuscripts

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Understanding men's psychological reactions and experience following a cardiac event: A qualitative study from the MindTheHeart Project

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- Word count (6356 words), excluding title page, abstract, references, figures and tables.

## Abstract:

**Objectives:** Emotional issues such as depression, anxiety, and post-traumatic stress disorder are common following a cardiac event. Despite their high prevalence, they often go undiagnosed and research suggests that men in particular are at higher risk. Therefore a better understanding of men's experiences with a cardiac event and ensuing health services is key for adapting approaches that meet their needs. The aim of this study was to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment. **Design** Qualitative study (focus groups and semi-structured interviews) using an interpretive phenomenal analysis.

Setting Clinical settings (Cardiac departments in hospitals, Cardiac rehabilitation programs and family medicine clinics) and in the community in three Canadian provinces. Participants A total of 93 men participated in the study through 22 focus groups and 5 semi-structured interviews. Results Four major themes emerged: 1) Managing uncertainty and adversity; 2) Distancing, normalizing, and accepting; 3) Conformity to traditional masculine norms; and 4) Social, literacy and communication challenges.

**Conclusions** Health professionals caring for men following a cardiac event must be aware of the psychological and social adjustments that accompany the physical challenges. However, there is a lack of explicit guidelines, tools and clinical training in men-sensitive approaches. Further research is required to better inform clinical practices and healthcare services.

#### Strengths and limitations of this study

This is the first large qualitative study in Canada that provides an in-depth understanding of psychological reactions and experiences in men following a cardiac event.

This study provides comprehensive insight into major dimensions that need to be considered in future intervention research that aims to improve men-sensitive psychocardiology services.

The qualitative data analysis process included a three-round approach to ensure intercoder reliability and to control for subjectivity.

This study did not include men from cultural minorities or Indigenous populations; hence, the findings may not have captured the needs and lived experiences of these populations.

We did not systematically recruit or conduct analyses by age, cardiac diagnosis or comorbities and different themes may have emerged across these factors. Also we did not take into account when the event had occurred in relation to the data collection, hence this may have introduced different perceptions if the event was recent vs more than a few years past.

#### **1. Introduction**

Emotional issues such as depression, anxiety, and post-traumatic stress disorder (PTSD) are common among patients who experience a major cardiac event (i.e. acute coronary syndrome (ACS)) [1]. Despite high prevalences, these symptoms and psychological disorders often go undiagnosed and contribute to an increased risk of related morbidity and mortality, as well as social and economic vulnerability [2]. Psychocardiology, or clinical psychology in cardiac settings, is the science and practice of applying psychological knowledge to the prevention, treatment, and rehabilitation of patients with cardiac disease [3]. From this perspective, psychological and cardiac issues are interdependently addressed by collaborative interprofessional teams through patient-centred approaches.

Stepped-care models include a continuum of mental health interventions and services required to provide adequate health services and support in the most cost-efficient manner, based on patients' needs and choices. These models have shown effectiveness with different health conditions, including cardiac disease [4–7]. However, the last two decades of research in psychocardiology show that less than 25% of men with ACS engage in secondary prevention delivered by cardiac rehabilitation centres, seek support, or use appropriate timely interventions for their psychological distress and mental health [8–10]. Implementing effective psychocardiology stepped-care services for this population would require taking into account the social and behavioural determinants of men's health. To our knowledge, no research has been conducted on the acceptability and feasibility of a stepped-care model approach to psychological treatment that has been specifically designed to be sensitive to the needs and expectations of men with cardiac disease.

The MindTheHeart program, an innovative psychocardiology intiative launched in three Canadian provinces, aims to improve the prevention, early detection, and treatment of depression, anxiety, and PTSD in men following a cardiac event. The cornerstone of this program was to design and test the feasibility and acceptability of a stepped-care approach to treatment structured into: Step 1: Psychoeducational intervention, Step 2: Group therapy including sessions with a significant other, and Step 3: Individual or couple therapy based on patient preference.

To appropriately design and tailor this stepped-care model to the needs of men following a cardiac event, it was essential to gain a better understanding of their experience with cardiac disease and existing health services (or lack thereof). For the purpose of this article, our aims are to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment.

#### 2. Methods

#### 2.1. Study design

A qualitative study was conducted using an inductive phenomenological qualitative approach to provide a detailed description of the experience of men with cardiac disease while staying true to the collected qualitative data [11,12]. The consolidated criteria for reporting qualitative research (COREQ) were used to structure this study and ensure its methodological quality [13].

#### 2.2. Participants

Convenience samples were recruited through cardiac rehabilitation programs and cardiac departments or clinics at teaching hospitals as well as in the community in three Canadian provinces: New Brunswick, Ontario and Quebec. To recruit participants we used a combination of both active (patient solicitation at participating cardiac rehabilitation programs and a snowball technique) and passive (radio broadcasts and advertisements in local newspapers) strategies. The inclusion criteria were: 1) to be 19 and over in New Brunswick, and 18 and over in Ontario and Quebec; 2) to have had a myocardial infarction, unstable angina, or heart surgery in the last 5 years with or without depression, anxiety or PTSD; 3) to be able to read and speak English or French; 4) to be able to provide informed consent; and 5) willing to participate in a group discussion. A sampling frame was developed to capture variation in age, marital status, cardiac health, mental health conditions, spoken language (French or English), and socioeconomic status.

#### 2.3. Data collection

Data collection took place between May 2016 and August 2017. The focus group qualitative technique was selected to gather information [12]. This technique is appropriate for exploring patients' experience and perspective through a collective discussion. Interactions and discussions between participants are encouraged. Experiences and opinions are shared and explored while participants are questioning or challenging one another or disagreeing with one another. Initially, only focus groups were planned, but due to challenges in recruiting a sufficient number of partipants (time constraints, limited availability due to summer vacations, reticence to partake in a group discussion), we also carried out a total of five (n=5) one-on-one semi-structured interviews to ensure inclusiveness. Focus group discussions were facilitated by two members of the research team using a discussion guide (See Appendix 1). A preliminary version of the guide was reviewed by four male patients (two French and two English) to assess its intelligibility and appropriateness. Psychology and medical research staff, including the authors, conducted the focus groups and semi-structured interviews.. The same interview guide was used for the semi-structured interviews, which were conducted either face-to-face or by telephone. Participants were aware of the study's aims and objectives. They had the opportunity to ask questions to the interviewers prior to giving written informed consent to participate. Focus groups and semi-structured interviews were conducted in English or French based on participants' preference and took place at either a hospital or university setting. Data collection continued until information and conceptual saturation was reached.

### 2.4. Data analysis

The audio-taped focus groups and semi-structured interviews from the three provinces were transcribed verbatim and anonymized. When available, the field notes taken by interviewees were included in the analysis. An interpretative phenomenological analysis (IPA) was used to guide the thematic analysis of the data [14,15]. IPA is an inductive qualitative content analysis that allows for the description of patterns without *a priori* theories or models to guide the analysis. The aim of IPA is to explore in depth the participants' personal experiences, their meaning for them, how they make sense of these experiences, and what they would recommend to better meet their needs. The analytic approach followed iterations of thematic content analysis and codes were created through open and axial coding to capture emergent themes [16].

To effectively manage the amount of collected data, we organized a collaborative analytic team. The first author was responsible for the data analysis management process including the development of the MindTheHeart manual for the qualitative study, the delivery of data analysis training sessions and the development of a codebook. She acted as a referee when needed. To ensure consistency in data analysis, 10% of the transcribed verbatims were randomly selected and four analysts independently coded 10% of the material. This strategy allowed the calculation of the inter-coder reliability [17]. The intercoder reliability check consisted of coding and comparing the findings of each of the coders (2X2). The Cohen coefficient was used to assess to what extent the data deviated from perfect reliability. A coefficient of 80% or more was considered appropriate. Once this was reached, we considered that all analysts were using the same interpretative approach and data were analysed in a complementary manner. We performed three rounds of inter-coder reliability tests and two rounds of data analysis training sessions to create a convergent analytic approach. The transcribed material was analyzed through a systematized analytic process under the shared server of NVivo11-Pro (QSR International, Doncaster, Victoria, Australia).

Patient and Public Involvement: Patients were not involved in the design of this study. Results were presented through public talks.

#### 3. Results

A total of 22 focus groups (88 men) and 5 semistructured interviews (5 men) were carried out. In total, 93 men participated across the three provinces. Each focus group consisted of three to six participants and lasted approximately 85 to 155 minutes (Mean= 147 minutes). The semi-structured interviews with single participants lasted between 60 and 90 minutes (Mean= 82 minutes). The sociodemographic characteristics of the partipants are presented in Table 1. In terms of mental health status, we asked the following question: "Are you suffering from a mental health issue?". In the New Brunswick sample, three men reported suffering from depression, two reported suffering from depression and anxiety, and one reported PTSD. In the Ontario sample, four men reported having anxiety, three reported depression and one indicated having anxiety and depression. In the Quebec sample, two declared anxiety and one noted depression. Being self-reported,

this information presents with obvious limitations (i.e. lack of precision in regards to diagnosis and severity, based on patient interpretation, missing data). In terms of heart disease, we asked the following question: "Are you suffering from, have you ever suffered . d. . c healt. . swick sam, y (eight had Cor, . n Quebec, six men , he Ontario sample, th. .ced an ACS. This informatk. .tations (as previously noted). from, or are you at risk of heart disease?". All participating men declared currently suffering from at least one cardiac health condition, and having experienced at least one cardiac event. In the New Brunswick sample, 24 had experienced an ACS and nine had undergone open heart surgery (eight had Coronary artery bypass grafting (CABG) and one had a valve replacement). In Quebec, six men declared an ACS and two had undergone open heart surgery. Of the Ontario sample, three declared having undergone heart surgery and 23 experienced an ACS. This information is again based on self-report, and thus presents with limitations (as previously noted).

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	Age range			Marital	Employment		
	(years)	Ethnicity	Education	status	status	Language	
New Brunswick							
Focus groups – (8 groups for a total of 37 men)	45 to 79	Caucasian: 37	Secondary: 17 College: 4 University: 16	Single: 3 Married: 25 Common law: 4 Divorced: 2 Widowed: 2 Widowed + Divorced: 1	Employed: 13 Retired: 18 Employed + retired: 1 Semi-Retired: Sick leave: 3 2	6 EN 2 FR	
Semi- structured interviews (4 men)	45 to 54	Caucasian: 4	Secondary: 1 College: 3	Single: 2 Married: 2	Employed: 3 Sick leave: 1	3 EN 1 FR	
Ontario							
Focus groups - (9 groups for a total of 36 men)	51 to 90	Caucasian: 34 Caucasian + Jewish: 1 Caucasian + First nation: 1	Primary: 3 Secondary: 2 College: 7 University: 24	Single: 1 Married: 19 Common law: 7 Separated: 2 Divorced: 7	Retired: 28 Sick leave: 3 Employed + retired: 5	4 EN 5 FR	
Quebec							
Focus groups - (5 groups for a total of 15 men)	45 to 75	Caucasian: 15	Primary: 2 Secondary: 4 College: 4 University: 5	Single: 2 Married: 9 Common Iaw: 4	Employed: 1 Retired: 12 Sick leave: 1 Unemployed: 1	1 EN 4 FR	
Semi- structured interview (1 man)	Not included to protect for privacy						

# Table 1 Sociodemographic characteristics of participants

EN: English; FR: French
Interpretive phenomenological analysis of the gathered qualitative data from the three provinces highlighted emotional issues, as well as patterns of psychosocial adjustment challenges, faced by men following a cardiac event. Emerging themes were categorized and are presented below. Quotes have been reproduced to illustrate key points. To preserve anonymity and confidentiality quotes were tagged using a pseudonym (male name). French quotes were translated into English for the purpose of this publication.

#### 3.1. Managing uncertainty and adversity

A temporal sequence emerged across data as being instrumental in affecting men's experience following a cardiac event.

#### "Not me, not now!" Denial reaction and delay in seeking help

Refusing to recognize the cardiac event and purposely delaying the hospital (emergency department) visit seems to be a prevailing behaviour among men. "I was working, my back got very sore, and I broke out in a cold sweat, but I finished my shift. I knew ... it was my heart. So, I went home, showered, ate a little bit and had my last cigarette, cause I'm a smoker." - Gérard. "I rolled over in bed a couple of times when I should've gone to the hospital. Cause I know my wife would freak out, she'd be worried about me, right? And I know I'd be in the hospital for 12 hours, which would mean I couldn't go to work the next day. So I'm just going to roll over and just, you know, roll the dice on this, on this event, today, and see how it goes." – Tim. "I was home with chest pains. Not pain, but just pressure in my chest. Never for a minute, for a second, did I clue in that I had a heart problem on Thursday. I went back to work on Friday. Same pain, but when I sat down and rested, it went away. On Saturday I was home. I started my power saw to cut branches on trees and cut down a tree, and clean up the yard. And I only went to the doctor on Tuesday of the following week. Expecting to go there and he would say "Take a few tests and you'll go back home and we'll call you in a few weeks". Well, it changedwhen he said 'You're not going anywhere. You're going to be here a few days'. And I realised I was stupid. I should've gone on Thursday." – Gary

Across discussions, two contrasting explanations for the denial reaction and delay in seeking help emerged: 1) the sense of invincibility perceived by younger men (30 to 50 years old), as they did not see themselves at risk and could not understand or accept why they suffered a cardiac event: "younger men are brought up to feel that they are a bit invincible, that you know, they're bullet proof and you know that doesn't happen to them" - Paul, as well as by older men who had previously recovered from severe illnesses such as a heart attack or a cancer and perceived themselves as warriors, "I survived a cancer before, I haven't much of a fear of dying"-Pat and 2) the sense of vulnerability expressed by men who described the cardiac event as a loss (of control, of power, of dignity, and of autonomy) or a fear (of receiving a life-treathening diagnosis, of permanent incapacity or disability, of early retirement, or of death). An additional explanation mentioned across groups was the competing priorities of daily living and putting others above self " it's hard to take time for yourself when you have a lot of obligations"- Marc. Stressing about the lack of time and being busy is used to positively

explain and justify the treatment-seeking delay behaviour. This type of avoidance behaviour in regards to seeking help was often perceived as being somewhat of a responsible and altruistic behaviour, thus making it more acceptable and meaningful and reinforcing the masculine gender role and its impact on engaging in help-seeking and treatment-seeking.

## "What am I doing here? What'd be my life once I'm back home?": The in-hospital journey

The hospital stay, whose length varied according to the severity of the cardiac event, was most often described as very difficult, involving sleepless nights, worries, fear of death, and sometimes anger. Having to "stay in bed" was depicted as a failure, a loss of power and confidence, or an unfair situation. "It changed my life totally. Like, you know, I was pretty confident, pretty, you know, I was a supervisor at my work, captain of my team, just, you know, that 10 feet tall and bulletproof. I wasn't there anymore, right?"- Jacques While reactions varied, one particular question transcended across groups: "what would be my life once at home?". The anxiety generated by this question was discussed in groups as an important concern.

Across groups, men typically shared that they were very satisfied with the care they received (i.e., procedures, medications, interactions with health professionals about their cardiac condition) during their hospital stay, but that one thing they tended to avoid discussing openly was their apprehension about life after hospitalization. Thus, uncertainty about life after hospitalization emerged as a dominant theme across groups when discussing in-hospital challenges. In-hospital uncertainty was further characterized by lack of, or inability to achieve, a clear understanding about the cardiac event, its impact on the body and daily functioning, eventual impact on one's job or employability, and risks in terms of survival (fear of death). The main reasons why men experienced anxiety in the form of uncertainty about the future were that they (a) did not understand, or accept, the cardiac event; (b) did not feel in control of their future (how things are going to evolve?); (c) were intimidated by unintelligible medical terminology and high-tech procedures; and (d) apprehended the adjustements and the changes to be implemented once at home. Uncertainty about the future was associated with lack of self-confidence and was exacerbated by poor health communication on the part of professionals and in some cases the patients themselves, who were often reticent to share their concerns or to ask questions. Communication behaviours on the part of health care providers such as speaking in general terms and referring to population statistics (as opposed to using more precise and personalized information), only communicating via short conversations in a shared room while patients are in bed (as opposed to creating opportunities for asking questions in a more confidential environment), or providing unclear explanations using medical jargon (as opposed to clear explanations in lay terms), appear to play a critical role in generating and exacerbating feelings of uncertainty and apprehension about the future.

#### "I'm not the man I used to be!": Post-hospital discharge

Returning home following a cardiac event was discussed as an important transitioning phase. Group discussions revealed that being told to "*slow down and stay home*," even for a short period, was often experienced as unacceptable and devaluing. Post-hospital discharge, especially in the early going, was associated with psychological distress, frustration, and discomfort related to adopting the recommended lifestyle changes (e.g., lower sodium intake, eating more fruits and vegetables, quitting smoking), resting at home, and daily medication intake. Lack of undertanding of medical advice and recommendations, lack of preparedness for the changes to be implemented, and the experience of having had a "brush with death" were mentioned as major stressors.

"You know, the thing that stuck in my mind the most, of this whole episode... I talked to the surgeon before the operation, and he went through all the steps of what's happening, and bottom line, there's a 2% chance that you're gonna die... That gets your attention"-Henry. "Like, this gentleman keeps saying "If it's your time to go, it's your time to go." But for me, I'm not saying that I'm more or less important, but I have a young kid, so when your doctor tells you that you better make sure that your will is fully done and your financial situation is good cause you're a ticking time bomb, at 40, I have a young kid and for me, it plays a lot in my head, right"-George. "What I found the hardest of all is before my operation and after, they told me what I could do, what I couldn't" -Virgile

Perceived control was identified as a dynamic cognitive process that fluctuated in response to the cardiac event. Men constantly attempted to retain or gain control during the rehabilitation phase and even beyond this period. Changes in environmental circumstances, such as being hospitalized for extended periods of time, re-hospitalization for complications and then being discharged home, impinged directly on their ability to feel in control of their daily lives. The process of gaining a better sense of control was facilitated by rationalizing, or making sense of a new phase in their treatment or illness prognosis or by gaining awareness of environmental challenges "once you accept that you are restricted in your physical abilities it gets easier"- Paul.

The post-hospital discharge and recovery process experience are mainly shaped by age, social connectedness (life partner, family, friends, and community involvement), psychological preparedness, personality, and economic status (finances, employment, etc.). Groups' narratives revealed that feelings of powerlessness and sleep disturbances were experienced at all stages of the rehabilitation process and were often associated with the fear of dying. *"I was afraid for a long time to go to sleep. I would stay up for like three days until somebody slept with me more or less, right? My girlfriend at the time, we didn't stay together every night, but if she wasn't with me, I wouldn't sleep. I was afraid to go to sleep and not wake up."*-Albert.

#### 3.2. Distancing, normalizing, and accepting

Men reported that stepping back and reflecting on their own emotional reactions and experiences helped them make sense of their changing lives post-cardiac event. Two

perpectives emerged : experiencing it as a personal failure and/or as an opportunity (a second chance for a better life). In both perspectives, they were ready to accept this new normality and were ready for adjustment. "Once you accept that you are restricted in your physical abilities it gets easier"-Bernard. They reported using various strategies (spirituality, religion, faith, praying, introspection, meditation) as means to help them make sense of their cardiac event and accept the situation "Well, I wouldn't say I was completely free of worry for myself. Like the day before surgery, I went up to Sainte-Anne-De-Beaupré and I went to confession. So I was, you know. I wasn't completely fearless, going in"-Paul. "Well you know there's a lot of factors that impact on getting better support, prayer… I think prayer is a big thing, faith is a big thing too, you need to go for help"-Jack. "Spirituality helps, it gives you strenghts and courage. I think it's a psychological thing"-Marc.

Increased awareness of one's mortality was described as a motivating factor to help them prioritize taking charge of their health. Redefining priorities with their life partner and family, or engaging in companionship was also described as helpful: "My wife as well was very helpful, which means, she was not entirely too sympathetic which is, this is what you need to do, you know (laughs)."-Patrick "Like she took care of all my meds. Prior to the surgery, she wouldn't even know what meds I was on. But after that, she was the one who knew what med, and when there were changes"- Albert.

After being stabilized medically, reactions varied among men. Groups discussed three main reactions: (a) processing and reflecting on the lived experience and engaging in adopting a healthy lifestyle as a personal or family challenge, (b) taking the necessary time to process the traumatic event (to absorb the shock and understand what was happening) and then gradually exploring options and implementing changes, and (c) resisting and ignoring recommendations, using self-reliance and continuing the same lifestyle as before the cardiac event. *"I disregarded anything that my doctors were telling me, and I said that I had to take control of my own situation."*-Charles

#### 3.3. Conformity to traditional masculine norms

Dominant masculine norms can affect perceptions, acceptance, and normalization of the psychological distress following a cardiac event as well as help-seeking behaviours and mental health services utilization. "Broken masculinity" emerged as a transversal theme illustrating how deeply "masculinity and virility" were affected following a cardiac event. The functional limitations (i.e. staying at home, not driving, not shovelling snow, not lifting heavy weights), prescribed by their doctor or that were consequences of their heart condition and related medication (i.e. erectile dysfunction), were experienced as a major loss of manhood "Well, weakness also. There's a role. You're the father, and there's a role. And there's responsibilities that go with that role. And you want to continue to do your job, as a father. And you don't want to show them that you're as vulnerable as you are at the moment. You kind of try to carry through. Which is tiring, cause then when they're gone, you're just wiped out. You just put everything. You put the whole day's energy into that session with them." – Jean-Pierre. Perceiving their social role as "family breadwinner" or "family strong pillar" prevented men from sharing their emotions and

worries to their children or relatives. The altruistic behaviours, such as protecting relatives from worries, are valued by men and are used as intrinsic strategies to regain selfconfidence and sense of manhood. *"Well, I have a 14 year old son, who looks up to me I'm sure. I'm his father. So, you know, sometimes when I'd see him, surely, I'd say after the surgery when you're really not feeling yourself... You have to put on a game face because you really don't want to show exactly how you feel to your children, cause they're going to worry."* - **Brian.** 

The tendency to view and label certain behaviours as "feminine" as opposed to "masculine" seems to be an aggravating factor in terms of delaying or avoiding seeking help and using mental health services "...women will tend much more to talk about it to their friends in regards to how they're feeling. Where a man, sometimes it's hard to share with your partner sometimes. You don't want to show that sign of weakness, and that's the way that I look at it." – **Bill** "Suddenly you go through a heart attack and you will be like that (clic) the man they expect you to be, I mean the open minded... the touchy feel... you know... talking about private things... with people you don't know, Oh wow! Not me..."-**Greg** "I find that women will talk to each other about emotions and how they feel. But how often do you go to work and sit down with one of your friends and start talking about your emotional problems? Not often. It's just something that men don't do"-**Alban** 

Men working in male-dominated workplaces (i.e., paramedics, police, military, construction, fishery industry) stressed the importance of educating people in their workplaces and of providing them with supportive tools and strategies. "*The other thing too is like, in the military, I was trained for 32 years to be macho. There's no such thing as being depressed or tired or... you know what I mean? You'd just go out and do your thing, that's just the way it was. And that training, today, is still instilled in me."*- Martin.

#### 3.4. Social, literacy, and communication challenges

Following a cardiac event, men felt they had to change certain patterns within their lives and adjust to changes in their role as life partners, parents, and employees. There was a perception of loss of confidence in their physical capabilities and functioning in family and work relationships. Low social connectedness and support before the cardiac event was discussed in groups as a risk factor for cardiac disease and mental illness and as associated with poor mental functioning and quality of life during the recovery period. The quality and the intensity of family relationships as well as those with friends and co-workers varied over the course of recovery post-cardiac event and were dependant on men's acceptance of the situation and their need for help. When discussing social support and its relevance for a healthy recovery, the necessary balance between expected and received support emerged as key. Indeed, while they found it sometimes difficult to share their thoughts and challenges with their relatives, men appreciated the attention, the compassion, the understanding, and the support of their life partner, family members, and friends. Supportive interpersonal relationships were viewed as helpful for breaking the cycle of distress and anxiety. The support received improved men's trust in their ability to deal with the cardiac event, the cardiac rehabilitation, and the necessary adjustments. However, men mentioned sometimes being irritated because of the overprotectiveness of some relatives. In particular, being under 'spouse's management', they felt that they had lost part of their personal space, their independence and manhood. "...All of a sudden, people feel, my wife in particular, well, here's somebody who's not an invalid, but we have to, you know, every time you do anything it's well, you shouldn't be doing this, you shouldn't be doing that, you shouldn't be... And that sort of affected me – it still does – more than any other things..." – Mark.

Sexual problems developed in the aftermath of the cardiac event, either functional ones related to their ability to sustain an erection or to ejaculate (often side-effects of medications), or psychological ones that involved fears of exacerbating their heart condition if they were to engage in sexual activity, were described as a major concern. *"Sexually, I'm not the man I used to be. It's just – and I blame it on the pills – it's just that my life has changed drastically...I keep toying with the idea that maybe I should stop taking the pills, but I know that it's gonna get me one way or the other... So... it's really finding a sweet spot with the right medication."-Wayne "you don't have anymore the sexual drive, you know, that you had before"-Martin* 

#### **Concerns about work**

As work is a significant aspect of personal and social identity, being on a long term sick leave may lead to feelings of shame and guilt or regarding oneself as incompetent, incapable, or physically weak. "I've been out of work for a year and a half. I don't want to go back there. I don't want the stress of it. In the meantime, my work's moving, so we're all going to lose our jobs anyways. I've been there 22 years. So it's just another stressor, right? And a lot of stuff outside of work, and it's a helpless feeling."-Paul. "I supervised the Giant Tiger warehouse. I couldn't do that anymore. You know what I mean? Stuff like that, you know? The only thing I do anymore is play baseball. That's just it..."-Richard. Early returning to work, even againt medical advice, is discussed as a problem-solving strategy to reinforce self-confidence and overcome stress. "The cardiologist came, he says, "well, we have to do a triple bypass". I looked at him, I said, "well, how long am gonna have to stay in the hospital?". He said, "two weeks". I says, "I don't have time for that. I have to be back at work for the 29th"-Serge "after my heart attack, the only thing I wanted to do was get better so I could go back to work, 'cause I'm only 52 and I need to work. So, that's all about"-Georges

#### Health literacy, health communication and health services navigation

Men's health literacy was pointed out as a major challenge. The lack of understanding medical jargon and procedures emerged as an additional stressor and was described as a barrier for asking questions and seeking more information, explanations, or advice. The bidirectional association between cardiac health and mental health was unclear and not fully understood. Moreover, mental illness signs, symptoms, and diagnostic labels seem to interfere with the masculine ideals. Indeed, men did not identify themselves as "depressed", "stressed", or "anxious" but used restrictive vocabulary to express emotional distress like "low energy", "challenged", or "meeting temporary difficulties".

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Men valued the quality and human kindness associated with healthcare providers they had access to and described how the interactions, the conversations, and the alliance they had with them enhanced their compliance with treatment plans and improved their general mental and physical health status. "…They gave me all the paperwork, all the stress things, charts and stuff, and my GP was great. She would ask me how my mental state was. I don't know guys like that. I appreciate it, but my doctors know her when I go in her office. She's in no hurry. If I'm sitting there crying for 15 minutes, she's there for 20 with me. So, yeah, I'm very lucky. I have great doctors…"- Serge

Men put a strong emphasis on the quality of communication they had with health professionals, such as being listened to, not being rushed, receiving care with sympathetic attitude, being trusted and taken seriously "I feel comfort. I feel comforted going to them. I really get a sense from my doctors that they really care about me."-William.

However, the lack of time allocated by physicians to address emotional distress and social challenges following a cardiac event was reported as a barrier for access to supportive and caring services: "You look at the doctor as being event-centered. In other words, he's there for a medical purpose. You have your 10 or your 15 minutes, and you're gone. You know, we're talking today about emotions, and this seems to be a time-consuming expensive exercise that at least the professionals I've dealt with haven't been available for. And you feel as though you're intruding on their importance, I guess, by, you know, having long chats and that sort of thing."-Patrick. Men felt pressured by time: "I just felt like I was just in and out like I was at a hair salon or something. You know, get this done, get the ECG done, and okay, see you later. Here's a prescription... I always felt like I was being rushed and brushed off. And so there was no relationship"-Mike. "You know, you've got your so many minutes. And I still think in our health system – and maybe not what's in the future – but if there was some minor pay for service, I think that would be helpful because you always feel you're on a sort of a diet of service. You're in; you're out, and of necessity. They move on to the next person."-Bruce.

The lack of knowledge about the health system and how to navigate services and manage medical information appeared to lead to the perception of the healthcare system as a "men-unfriendly space" where they feel discomfort and uncertainty: "I think there's a problem with men as a whole, and you know, women seem so much more in tune with, you know, going to see the doctor for themselves, child birth, kids, I mean, when my son was ill, I never went to the doctor with him, my wife took him and it just wasn't a place I'd go; didn't know him very well, didn't know much about what to tell him"-Philip. Moreover, the perceived conflicting information received from different health professionals increased anxiety and stress about how to manange health conditions and how to use health services. Men participating in cardiac rehabilitation programs reported the benefits of social interaction with other cardiac patients, identified as the "cardiac family". Sharing a similar health condition helps to normalize the challenges and accepting the "new reality".

#### 4. Discussion

This study aimed to describe the emotional issues and understand the patterns of psychosocial adjustment experienced by men following a cardiac event. Across the three Canadians provinces, participants showed homogeneity in reported experiences of the cardiac event, and its subsequent psychological reaction and social impact. Adaptation to the event, both psychologically and socially, did not appear to relate to geographical location but rather to intra-individual experiences and differences (ie., cultural norms, beliefs, relationships, etc.)... In the focus groups men opened up readily about their emotions and their vulnerabilities. They shared their experiences and difficulties in adapting and adjusting to their "new post-cardiac identity" as well as the need to accept new roles. They acknowledged that this adjustment needed to be worked out with their environment, their home, their family, their friends, and their workplace. Most often they found support through their partners and through peer support when they attended cardiac rehabilitation sessions. The focus group sessions helped to validate and normalize their initial reactions. They regretted that the health professionals they had encountered had not enquired in a systematic way about their mental well-being as they would about their physical symptoms or diet or exercice. This is certainly on aspect of practice that would be pertinent for health professionals to change.

One important overarching element that was brought forth by men was the lack of systematic attention given by healthcare professionals to the psychological consequences of having experienced a cardiac event. It was suggested that some professionals may bring up the subject, but in most instances, the question was not asked. Therefore, there seems to be a lack of consistency within the health system in regards to the attention paid to the psychological sequelae of heart disease. These aspects were reported in previous studies on various health conditions [18–20]. However, there is still a lack of clear and evidence-based guidelines and resources to support men-sensitive health communication as well as clinical practices to foster men's mental health. This study also revealed how traditional masculine norms can affect the way men experience and seek help for emotional distress following a cardiac event, and how these behaviours affect their health and wellbeing. Tailoring and targeting clinical interventions may increase men's service uptake and the efficacy of treatments. Specific factors associated with men's access to, and engagement with mental health care are critical to increasing help-seeking, treatment uptake, and effectual self-management among men experiencing emotional distress following a cardiac event.

While the literature contains extensive reports on "toxic masculinity" as a major determinant of men's health [21] or its impact on help-seeking in men [22], our study revealed "broken masculinity" to be an untold and unrecognized distress following a cardiac event. We found that men experienced a great deal of psychological anguish over the changes imposed by their cardiac illness, and that these changes were directly related to their sense of themselves as men in their family and in society. Our results confirm, as suggested by previous research, that it will be crucial to address these

concerns in a systematic way in order to combat symptoms of depression, anxiety, and post-traumatic stress in men following a cardiac event [23,24].

Our results corroborate and extend what other researchers have found concerning the psychological impact of a cardiac event. The sense of uncertainty, stress, discouragement, and sometimes hopelessness that many men in our sample talked about as they struggled to come to terms with heart disease and its effects on their personal and professional lives is consistent with the elevated levels of depression, anxiety, and post-traumatic stress reported among men (and women) elsewhere in the literature [1,2]. This sense of "broken masculinity" might be dangerous because it reflects, among other things, an espousal of attitudes and values that emphasize self-sufficiency and strength to such a degree that men refrain from addressing concerns related to their physical and mental health. Indeed, the results of previous studies [8,10] have indicated that traditional attitudes of this nature are related to poorer health outcomes in men than in women.

The lack of readily accessible and understandable information on the mental health aspects of heart disease that we noted in this study, along with the emotional, professional, and interpersonal challenges that men discussed, suggest that healthcare providers need to be better informed not only of the psychological consequences of heart disease but also of gender-specific ways of coping with them. Although there are examples of some initiatives that move in this direction (e.g., the Canadian Rehabilitation Network of Ontario, the Atlantic Cardiac Rehabilitation Network), to our knowledge there is not yet a comprehensive strategy for addressing themes like "broken masculinity" in male cardiac patients. For this reason, it is imperative to develop and implement interventions that will take into account the psychological impact of heart disease on men's sense of self, their relationships, and their work, along with the importance of adopting more flexible attitudes about what it means to be a man (i.e., a strong man asks for help when he needs it; a strong man takes care of himself and of others).

#### Limitations

The participants in this study were mostly in their sixties and over, which is representative of the population of men with cardiac disease. However, it would be of interest to study more specifically cardiac disease in men in their 30s, 40s, or 50s as cardiac disease is becoming more prevalent in these men.

The participants in our study were essentially white, with little or no representation of other ethnic groups or indigenous people. This may not be representative of larger urban Canadian settings.

Although our inclusion criteria indicated a cardiac event in the last 5 years, for some participants, the first event may have occurred some 10 years prior and there may have been changes in cardiac rehabilitation programs and health services. Moreover, the

responsiveness of health professionals at the time may have been different. A quantitative study exploring these aspects may allow to retrieve accurate information.

#### Strengths

This study is the first of its kind to delve into the subjective experience of men with heart disease and to examine the link between their reactions to their cardiac event and their mental health. We were able to detect key themes that are likely to resonate with most men who have heart disease, which could serve as a foundation for the development of intervention programs, i.e. the stepped-care model.

#### 5. Conclusion

This paper highlights the significant emotions that arise following a cardiac event and how men attempt to counter them as best as they can. It is known that men have a tendency not to talk about their emotions or to express them differently than women do. Health professionals caring for men in these contexts must be aware of this and receive training in gender-sensitive approaches. It will be important to systematically inform their patients of the possible occurrence of such emotions as well as the tools and ressources to self-manage as a first step. Considering the impact on morbidity and mortality when anxiety, depression, or post-traumatic stress are in the diagnostic picture, cardiologists, cardiac surgeons and family physicians as well as psychologists and other health professionals involved in cardiac rehabilitation programs must be ready to systematically inquire and to screen their patients for common mental health conditions. Improved mental health of these patients will most likely improve their cardiac disease. A larger study is underway to longitudinally investigate the need for emotional support among men following a cardiac event as well as exploring acceptability and feasibility of mensensitive stepped-care models.

**Ethical approval** The study received ethical approval from the research ethics boards (REB) of the participating study sites: Réseau de santé horizon : 2016-2295; Réseau de santé Vitalité : 2016-04-13; Université de Moncton : 1516-047; Hôpital Montfort : JJ-04-11-15; Institut de cardiologie de l'Université d'Ottawa : 2014-1801 (#projet), formulaire F11-4318; Université de Montréal : MP-33-2016-2006 (# projet), demande # F0-7529; and Hôpital de Hull : 2016-159 (# projet). All participants signed a confidentiality and consent form.

Acknowledgements The authors would like to thank the staff of the participating cardiac rehabilitation programs for their support with men recruitment, and the research staff (Arielle Doiron, Lise Gallant, Sarah Nowlan, Vanessa Tassé and Mireille Ntambwe) for their contribution in the transcription of verbatims, the data organization and the preliminary coding. The authors would also like to thank the men who have contributed to the focus groups and semi-structured interviews.

**Funding** This paper represents independent research, for which authors received funding from the Movember Foundation-Canada and from the New Brunswick Health Research Foundation. JJ would also like to acknowledge the logistic and financial support provided by the Centre de formation médicale du Nouveau-Brunswick to support this publication.

**Competing interests** None declared.

**Contributorship statement** All authors (Jalila Jbilou, Jean Grenier, Marie-Hélène Chominenne, France Talbot, Heather Tullock, Bianca D'Atono and Paul S. Greenman) have contributed significantly to the design of the project, the planning and the conduct of the data collection, they participated to the team work for the analysis of the data (development of the codebook, training of the research assistants (for first coding and codes' organization), discussions if consensus was not achieved and worked collaboratively on 2<sup>nd</sup> coding and conceptual categorization) and the discussion of the results. Jalila Jbilou and Jean Grenier prepared the first manuscript draft; all authors contributed to, review and approve the final manuscript.

Data sharing statement All transcripts have been de-identified following ethical recommendations to protect participants' privacy and confidentiality. Unfortunately, we do not have consent from participants to share the full denominated data publicly. However, Codebooks or sections of the transcripts can be requested by contacting the corresponding author.

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#### **APPENDIX 1**

#### « MIND THE HEART » PROJECT

#### FOCUS GROUP DISCUSSION GUIDE

#### **ENGLISH VERSION**

#### INTRODUCTION

Thank you for agreeing to participate in this focus group discussion. This discussion is part of a multi-site participatory action research project, « MindTheHeart », funded by Movember Foundation Canada and the New Brunswick Health Research Foundation that aims at raising awareness for psychologically healthy workplaces for men living with or at risk of HD.

The purpose of this focus group is for the research team to understand the needs, expectations and preferences of men at risk of or living with HD, with regard to interventions such as mental health promotion, mental health prevention, and mental health interventions for MD/AD/TRD. The information gathered will help the research team to design interventions that meet the specific needs of men with HD to prevent or early detect and treat co-occurring mental health issues.

Before we start the discussion, allow us to clarify some points.

1. Could you all kindly verify that you have already signed the consent forms stating your voluntary participation in this focus group?

Yes 🗆

No 🗆

- 2. The duration of the focus group discussion will take 90 to 120 minutes in which you have the right to leave the group at any point in time.
- 3. The whole session will be audio recorded to ensure the accuracy of the information that you provide. However the consent forms that you have signed will ensure that all the information that you share today shall be confidential and anonymous.
- 4. Please note that each of you confirms that you are aware that anything said during the meeting has to be kept confidential and that you understand that you are not allowed to disclose any information or any names related to this focus group.

<sup>38</sup> Would anyone like to ask any question or has any clarification related to this focus group before we start?

Before we start, could you please take a few minutes to complete this general information sheet? (Give them the information sheet below)

52					
53	Date: _	 	 	 	
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The objective of the following form is to collect general information about you. You can be assured that the information collected will remain confidential and anonymous.

3 4	1-	Age
5 6 7	2-	City of residence
7 8 9 10 11 12 13 14 15	3-	Familial status (tick as apply). Single (never married) Married Common law partner Divorced Widow Other (specify):
17 18 19 20 21 22 23 24	4-	Level of education: (tick as apply). Mot schooled Primary Secondary College University Other (specify):
26 27 28 29 30	5-	Employment status: (tick as apply). Employed Retired Sick leave
31 32 33 34 35 36 37	6-	Preferred language for health services (tick all that applies). French English Others (specify):
57 38 39 40 41 42 43 44 45 46 47 48	7-	What is your ethnicity? (tick all that applies). White/Caucasien Black (ex., Haitian, African, Jamaican, Somalia) Latino/Hispanic Asiatic (ex., Chinese, Japanese, Vietnamese) Middle East Native/First Nation/Mixed-Race Pacific Island Other (specify):
49 50	<u>Health</u>	status
51 52 53 54	1-	Are you suffering from, have you ever suffered from or are you at risk of heart disease? (if yes, please specify)
55 56 57 58	2-	Are you suffering from a mental health issue? (if yes, please specify)
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

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### FOCUS GROUP DISCUSSION GUIDE

#### A. Patient Experience 2 How would you describe your experience with the mental health issues that you have been experiencing following your 3 4 HD? 5 Physical well-being (performing your daily activities, energy levels and physical activity) 6 Emotional well-being (interest in sex, experienced feelings, mood and relationships with others) \_ 7 Mental health issues (mood and anxiety, ability to make 'good' decisions and be productive) 8 Financial situation 9 Employment situation (absence from work, productivity, demotions, arguments with colleagues and supervisors, 10 stigma, loss (advantages, respect, confidence...)) 11 For many men, self-reliance and being competitive are important characteristics. How about you? What are \_ 12 important manly characteristics for you? How might that have changed with HD and mental health issues? 13 How do you deal with those changes? \_ 14 15 **B.** Health Promotion and Prevention Needs 16 What do you know about the link between HD and mental health issues in men? 17 Health literacy/Knowledge/Health education 18 What do you wish you had known or done that might have helped you avoid HD and mental health issues? 19 For other men experiencing HD and mental health issues, what are the most important pieces of information about \_ 20 the link between HD and mental health issues and how might they be best conveyed? 21 Regarding risk reduction for HD and mental health issues: What kind of information about mental health and HD do you 22 23 think will be most useful for you? 24 Type of information (statistics, recommendations, health advice, explanations...) 25 Communication channels: (read, audio or visual media, seminars, peer education, educational materials, others \_ 26 specify...) 27 Location of information delivery (workplace, health care services, community, media) \_ 28 Timeliness of information delivery (moment/delay) 29 Websites, apps, social media, men testimonies as a source of information, interest and use \_ 30 31 C. Health Services and Clinical Care 32 What is your experience with the health care that you were provided due to your HD and mental health issues needs in the 33 last five years? 34 How connected are you to the health care system and specialist heart and mental health services? 35 Relevance of care: Many men tell us they don't want to rely on medications to ensure their mental health or treat 36 specific ailments such as depression? What is your perspective/experience? What is your advice to health care 37 providers about working with male patients who have experienced HD and/or mental health issue? 38 Utilization of services: Lots of men are reticent to use professional mental health services – why might that be? 39 What about you, what challenges did you have in seeking heart or mental health care? 40 Availability and access to care? (existence of men-sensitive services, factors related to utilization of services: \_ 41 psychologist, insurance coverage, social services...) 42 43 What were some of the areas that you suggest be improved? (your expectations) 44 Could you please describe your experience with your health care professional (family doctor, cardiologist, nutritionist, 45 kinesiologist, social worker, psychologist, and counselor) regarding information about mental health issues and heart 46 disease? 47 Information/Education provided: What type of patient are you? One who likes to be told what to do or would you -48 rather be more involved in the decision making and strategies? Please provide an example of that round your HD 49 and/or mental health issues? 50 Perceived expectations and needs 51 Patient/Clinicians dynamics (communication, relationship, openness, empathy and shared-decision making) 52 Proposed improvements: Can you provide an example of a positive interaction/relationship with a specific health 53 care professional? What are the characteristics of a great health care professional? 54 How does the gender of the health care professional influence that relationship? 55 Some men like to lead – others like clear instructions. What is your preference and experience of interacting with \_ 56 health care professional? 57 58 3 59 For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml 60

## Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

### YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	All authors conducted the focus group or the semi-structured interview	Method- Page4
2. Credentials	JJ PhD, MD JG PhD, CPsych MHC MSc, MD FT PhD, LPsych HT CPsych BD'A PhD PSG PhD, CPsych	Title page-1
3. Occupation	What was their occupation at the time of the study? Researchers, Clinicians or both.	-
4. Gender	Was the researcher male or female? Males (JG, PSG) and Females (JJ, MHC, FT, HT, BD'A)	-
5. Experience and training	What experience or training did the researcher have? A MindTheHeart manual for the qualitative study was developed. Training was offered to the researchers and the research staff involved in this study.	Methods-Page 5
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement? No	-
7. Participant knowledge of the interviewer	What did the participants know about the researcher? Ethical approval had been granted from REB in all participating sites.	Ethical approval- Page 15-16
	information sheet and had the opportunity to ask their questions to the interviewers prior to giving their written informed consent.	Method-Page4

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8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	-
Domain 2: study design		
Theoretical framework		
9 Methodological	What methodological orientation was	Methods Dage 5
orientation and Theory	stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis Open and axial coding with interpretative phenomenological analysis.	Methods-rage 5
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball Convenience samples The inclusion criteria were: 1) to be 19 and over in New-Brunswick, and 18 and over in Ontario and Quebec; 2) to have had a myocardial infarction, unstable angina, or heart surgery in the last 5 years with or without depression, anxiety or PTSD; 3) to be able to read and speak English or French; and 4) to be willing to participate in a group discussion.	Methods-Page 4
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email To recruit participants we used a combination of active strategies (patients' solicitation at participating cardiac rehabilitation programs and a snowball technique) and passive strategies (radio broadcasts and local newspapers advertisement).	Methods-Page 4
12. Sample size	How many participants were in the study? 93 men	Results-Page 5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	-
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace At the University or the hospital	Methods-Page 4
15. Presence of non- participants	Was anyone else present besides the participants and researchers? No	-
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date Data presented in a Table (Table 1)	Results-Page 6

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Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Yes	Appendix1 Guide
	Was it pilot tested? The guide was reviewed by four patients who did not participate to the study.	Method-Page 4
18. Repeat interviews	Were repeat inter views carried out? If yes, how many? No	-
19. Audio/visual recording	Did the research use audio or visual recording to collect the data? Audio	Methods-Page 4
20. Field notes	Were field notes made during and/or after the inter view or focus group? Yes	Methods-Page 5
21. Duration	What was the duration of the inter views or focus group? Each focus group consisted of three to six participants and lasted approximately two hours (+/- 35 minutes). The semi-structured interview lasted between 60 and 90 minutes.	Results-Page 5
22. Data saturation	Was data saturation discussed?	Methods-Page 4
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction? No	-
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data? 12 coders	Methods-Page 5
25. Description of the coding tree	Did authors provide a description of the coding tree? No	-
26. Derivation of themes	Were themes identified in advance or derived from the data? Derived from the data	Methods-Page 5
27. Software	What software, if applicable, was used to manage the data?	NVivo 11 Pro
28. Participant checking	Did participants provide feedback on the findings? Yes	Strengths and limitations
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number Yes	Results
30. Data and findings consistent	Was there consistency between the data presented and the findings? Yes, mainly	Discussion
31. Clarity of major themes	Were major themes clearly presented in the findings? Yes	Results
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes? Yes	Discussion

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#### Understanding men's psychological reactions and experience following a cardiac event: A qualitative study from the MindTheHeart Project

Journal:	BMJ Open
Manuscript ID	bmjopen-2019-029560.R2
Article Type:	Original research
Date Submitted by the Author:	07-Sep-2019
Complete List of Authors:	Jbilou, Jalila; Universite de Moncton, Psychology; Universite de Moncton, Centre de formation médicale du Nouveau Brunswick Grenier, Jean; Hopital Montfort, Institut du Savoir Montfort Chomienne, Marie-Helene; University of Ottawa, Family Medicine; University of Ottawa, School of Epidemiology and Public Health Talbot, France; Universite de Moncton, Psychology Tulloch, Heather; University of Ottawa, University of Ottawa Heart Institute, Cardiac Prevention and Rehabilitation D'Antono, Bianca; Universite de Montreal, Psychology Department and Research Centre at the Montreal Heart Institute Greenman, Paul; Universite du Quebec en Outaouais, Département de Psychoéducation et de Psychologie; Hopital Montfort, Institut du Savoir Montfort
<b>Primary Subject Heading</b> :	Mental health
Secondary Subject Heading:	Qualitative research
Keywords:	Depression & mood disorders < PSYCHIATRY, QUALITATIVE RESEARCH, REHABILITATION MEDICINE, Coronary heart disease < CARDIOLOGY, Ischaemic heart disease < CARDIOLOGY, Myocardial infarction < CARDIOLOGY
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#### SCHOLARONE<sup>™</sup> Manuscripts

Understanding men's psychological reactions and experience following a cardiac event: A qualitative study from the MindTheHeart Project

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- Word count (6356 words), excluding title page, abstract, references, figures and tables.

#### Abstract:

**Objectives:** Emotional issues such as depression, anxiety, and post-traumatic stress disorder are common following a cardiac event. Despite their high prevalence, they often go undiagnosed and research suggests that men in particular are at higher risk. Therefore a better understanding of men's experiences with a cardiac event and ensuing health services is key for adapting approaches that meet their needs. The aim of this study was to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment. **Design** Qualitative study (focus groups and one-on-one interviews) using an interpretive phenomenal analysis.

Setting Clinical settings (Cardiac departments in hospitals, Cardiac rehabilitation programs and family medicine clinics) and in the community in three Canadian provinces. Participants A total of 93 men participated in the study through 22 focus groups and 5 semi-structured interviews, none have been excluded based on comorbidities. Results Four major themes emerged: 1) Managing uncertainty and adversity; 2) Distancing, normalizing, and accepting; 3) Conformity to traditional masculine norms; and 4) Social, literacy and communication challenges. Conclusions Health professionals caring for men following a cardiac event must be aware of the psychological and social adjustments that accompany the physical challenges. However, there is a lack of explicit guidelines, tools and clinical training in men-sensitive approaches. Further research is required to better inform clinical practices and healthcare services.

#### Strengths and limitations of this study

This is the first large qualitative study in Canada that provides an in-depth understanding of psychological reactions and experiences in men following a cardiac event.

This study provides comprehensive insight into major dimensions that need to be considered in future intervention research that aims to improve men-sensitive psychocardiology services.

The qualitative data analysis process included a three-round approach to ensure intercoder reliability and to control for subjectivity.

This study did not include men from cultural minorities or Indigenous populations; hence, the findings may not have captured the needs and lived experiences of these populations.

We did not systematically recruit or conduct analyses by age, cardiac diagnosis or comorbities and different themes may have emerged across these factors. Also we did not take into account when the event had occurred in relation to the data collection, hence this may have introduced different perceptions if the event was recent vs more than a few years past.

#### 1. Introduction

Emotional issues such as depression, anxiety, and post-traumatic stress disorder (PTSD) are common among patients who experience a major cardiac event (i.e. acute coronary syndrome (ACS)) [1]. Despite high prevalences, these symptoms and psychological disorders often go undiagnosed and contribute to an increased risk of related morbidity and mortality, as well as social and economic vulnerability [2]. Psychocardiology, or clinical psychology in cardiac settings, is the science and practice of applying psychological knowledge to the prevention, treatment, and rehabilitation of patients with cardiac disease [3]. From this perspective, psychological and cardiac issues are interdependently addressed by collaborative interprofessional teams through patient-centred approaches.

Stepped-care models include a continuum of mental health interventions and services required to provide adequate health services and support in the most cost-efficient manner, based on patients' needs and choices. These models have shown effectiveness with different health conditions, including cardiac disease [4–7]. However, the last two decades of research in psychocardiology show that less than 25% of men with ACS engage in secondary prevention delivered by cardiac rehabilitation centres, seek support, or use appropriate timely interventions for their psychological distress and mental health [8–10]. Implementing effective psychocardiology stepped-care services for this population would require taking into account the social and behavioural determinants of men's health. To our knowledge, no research has been conducted on the acceptability and feasibility of a stepped-care model approach to psychological treatment that has been specifically designed to be sensitive to the needs and expectations of men with cardiac disease.

The MindTheHeart program, an innovative psychocardiology intiative launched in three Canadian provinces, aims to improve the prevention, early detection, and treatment of depression, anxiety, and PTSD in men following a cardiac event. The cornerstone of this program was to design and test the feasibility and acceptability of a stepped-care approach to treatment structured into: Step 1: Psychoeducational intervention, Step 2: Group therapy including sessions with a significant other, and Step 3: Individual or couple therapy based on patient preference.

To appropriately design and tailor this stepped-care model to the needs of men following a cardiac event, it was essential to gain a better understanding of their experience with cardiac disease and existing health services (or lack thereof). For the purpose of this article, our aims are to describe the self-reported emotional challenges that men face following a cardiac event and to understand their patterns of psychosocial adjustment.

#### 2. Methods

#### 2.1. Study design

A qualitative study was conducted using an inductive phenomenological qualitative approach to provide a detailed description of the experience of men with cardiac disease while staying true to the collected qualitative data [11,12]. The consolidated criteria for reporting qualitative research (COREQ) were used to structure this study and ensure its methodological quality [13].

#### 2.2. Participants

Convenience samples were recruited through cardiac rehabilitation programs and cardiac departments or clinics at teaching hospitals as well as in the community in three Canadian provinces: New Brunswick, Ontario and Quebec. To recruit participants we used a combination of both active (patient solicitation at participating cardiac rehabilitation programs and a snowball technique) and passive (radio broadcasts and advertisements in local newspapers) strategies. The inclusion criteria were: 1) to be 19 and over in New Brunswick, and 18 and over in Ontario and Quebec; 2) to have had a myocardial infarction, unstable angina, or heart surgery in the last 5 years with or without depression, anxiety or PTSD; 3) to be able to read and speak English or French; 4) to be able to provide informed consent; and 5) willing to participate in a group discussion. A sampling frame was developed to capture variation in age, marital status, cardiac health, mental health conditions, spoken language (French or English), and socioeconomic status.

#### 2.3. Data collection

Data collection took place between May 2016 and August 2017. The focus group qualitative technique was selected to gather information [12]. This technique is appropriate for exploring patients' experience and perspective through a collective discussion. Interactions and discussions between participants are encouraged. Experiences and opinions are shared and explored while participants are questioning or challenging one another or disagreeing with one another. Initially, only focus groups were planned, but due to challenges in recruiting a sufficient number of partipants (time constraints, limited availability due to summer vacations, reticence to partake in a group discussion), we also carried out a total of five (n=5) one-on-one semi-structured interviews to ensure inclusiveness. Focus group discussions were facilitated by two members of the research team using a discussion guide (See Appendix 1). A preliminary version of the guide was reviewed by four male patients (two French and two English) to assess its intelligibility and appropriateness. Psychology and medical research staff, including the authors, conducted the focus groups and semi-structured interviews.. The same interview guide was used for the semi-structured interviews, which were conducted either face-to-face or by telephone. Participants were aware of the study's aims and objectives. They had the opportunity to ask questions to the interviewers prior to giving written informed consent to participate. Focus groups and semi-structured interviews were conducted in English or French based on participants' preference and took place at either a hospital or university setting. Data collection continued until information and conceptual saturation was reached.

#### 2.4. Data analysis

The audio-taped focus groups and semi-structured interviews from the three provinces were transcribed verbatim and anonymized. When available, the field notes taken by interviewees were included in the analysis. An interpretative phenomenological analysis (IPA) was used to guide the thematic analysis of the data [14,15]. IPA is an inductive qualitative content analysis that allows for the description of patterns without *a priori* theories or models to guide the analysis. The aim of IPA is to explore in depth the participants' personal experiences, their meaning for them, how they make sense of these experiences, and what they would recommend to better meet their needs. The analytic approach followed iterations of thematic content analysis and codes were created through open and axial coding to capture emergent themes [16].

To effectively manage the amount of collected data, we organized a collaborative analytic team. The first author was responsible for the data analysis management process including the development of the MindTheHeart manual for the qualitative study, the delivery of data analysis training sessions and the development of a codebook. She acted as a referee when needed. To ensure consistency in data analysis, 10% of the transcribed verbatims were randomly selected and four analysts independently coded 10% of the material. This strategy allowed the calculation of the inter-coder reliability [17]. The intercoder reliability check consisted of coding and comparing the findings of each of the coders (2X2). The Cohen coefficient was used to assess to what extent the data deviated from perfect reliability. A coefficient of 80% or more was considered appropriate. Once this was reached, we considered that all analysts were using the same interpretative approach and data were analysed in a complementary manner. We performed three rounds of inter-coder reliability tests and two rounds of data analysis training sessions to create a convergent analytic approach. The transcribed material was analyzed through a systematized analytic process under the shared server of NVivo11-Pro (QSR International, Doncaster, Victoria, Australia).

Patient and Public Involvement: Patients were not involved in the design of this study. Results were presented through public talks.

#### 3. Results

A total of 22 focus groups (88 men) and 5 semistructured interviews (5 men) were carried out. In total, 93 men participated across the three provinces. Each focus group consisted of three to six participants and lasted 85 to 155 minutes (Mean= 147 minutes). The semistructured interviews with single participants lasted between 60 and 90 minutes (Mean= 82 minutes). The sociodemographic characteristics of the partipants are presented in Table 1. In terms of mental health status, we asked the following question: "Are you suffering from a mental health issue?". In the New Brunswick sample, three men reported suffering from depression, two reported suffering from depression and anxiety, and one reported PTSD. In the Ontario sample, four men reported having anxiety, three reported depression and one indicated having anxiety and depression. In the Quebec sample, two declared anxiety and one noted depression. Being self-reported, this information **BMJ** Open

presents with obvious limitations (i.e. lack of precision in regards to diagnosis and severity, based on patient interpretation, missing data). In terms of heart disease, we asked the following question: "Are you suffering from, have you ever suffered from, or are you at risk of heart disease?". All participating men declared currently suffering from at least one cardiac health condition, and having experienced at least one cardiac event. In the New Brunswick sample, 24 had experienced an ACS and nine had undergone open heart surgery (eight had Coronary artery bypass grafting (CABG) and one had a valve replacement). In Quebec, six men declared an ACS and two had undergone open heart surgery. Of the Ontario sample, three declared having undergone heart surgery and 23 experienced an ACS. This information is again based on self-report, and thus presents with limitations (as previously noted).

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	Age range (years) Mean age (+/-SD)	Ethnicity	Education	Marital status	Employment status	Language	
New Brunswic	New Brunswick						
Focus groups – (8 groups for a total of 37 men)	45 to 79 64.2 (+/- 9.7)	Caucasian: 37	Secondary: 17 College: 4 University: 16	Single: 3 Married: 25 Common law: 4 Divorced: 2 Widowed: 2 Widowed + Divorced: 1	Employed: 13 Retired: 18 Employed + retired: 1 Semi-Retired: Sick leave: 3 2	6 EN 2 FR	
Semi- structured interviews (4 men)	45 to 54 51.5 (+/- 4.8)	Caucasian: 4	Secondary: 1 College: 3	Single: 2 Married: 2	Employed: 3 Sick leave: 1	3 EN 1 FR	
Ontario				-	-	-	
Focus groups - (9 groups for a total of 36 men)	51 to 90 65.8 (+/- 15.5)	Caucasian: 34 Caucasian + Jewish: 1 Caucasian + First nation: 1	Primary: 3 Secondary: 2 College: 7 University: 24	Single: 1 Married: 19 Common law: 7 Separated: 2 Divorced: 7	Retired: 28 Sick leave: 3 Employed + retired: 5	4 EN 5 FR	
Quebec		1				•	
Focus groups - (5 groups for a total of 15 men)	45 to 75 67.5 (+/- 8.9)	Caucasian: 15	Primary: 2 Secondary: 4 College: 4 University: 5	Single: 2 Married: 9 Common law: 4	Employed: 1 Retired: 12 Sick leave: 1 Unemployed: 1	1 EN 4 FR	
Semi- structured interview (1 man)	Not included to protect for privacy						

#### Table 1 Sociodemographic characteristics of participants

EN: English; FR: French

Interpretive phenomenological analysis of the gathered qualitative data from the three provinces highlighted emotional issues, as well as patterns of psychosocial adjustment challenges, faced by men following a cardiac event. Emerging themes were categorized and are presented below. Quotes have been reproduced to illustrate key points. To preserve anonymity and confidentiality quotes were tagged using a pseudonym (male name). French quotes were translated into English for the purpose of this publication.

#### 3.1. Managing uncertainty and adversity

A temporal sequence emerged across data as being instrumental in affecting men's experience following a cardiac event.

#### "Not me, not now!" Denial reaction and delay in seeking help

Refusing to recognize the cardiac event and purposely delaying the hospital (emergency department) visit seems to be a prevailing behaviour among men. "I was working, my back got very sore, and I broke out in a cold sweat, but I finished my shift. I knew ... it was my heart. So, I went home, showered, ate a little bit and had my last cigarette, cause I'm a smoker." - Gérard. "I rolled over in bed a couple of times when I should've gone to the hospital. Cause I know my wife would freak out, she'd be worried about me, right? And I know I'd be in the hospital for 12 hours, which would mean I couldn't go to work the next day. So I'm just going to roll over and just, you know, roll the dice on this, on this event, today, and see how it goes." – Tim. "I was home with chest pains. Not pain, but just pressure in my chest. Never for a minute, for a second, did I clue in that I had a heart problem on Thursday. I went back to work on Friday. Same pain, but when I sat down and rested, it went away. On Saturday I was home. I started my power saw to cut branches on trees and cut down a tree, and clean up the yard. And I only went to the doctor on Tuesday of the following week. Expecting to go there and he would say "Take a few tests and you'll go back home and we'll call you in a few weeks". Well, it changedwhen he said 'You're not going anywhere. You're going to be here a few days'. And I realised I was stupid. I should've gone on Thursday." – Gary

Across discussions, two contrasting explanations for the denial reaction and delay in seeking help emerged: 1) the sense of invincibility perceived by younger men (30 to 50 years old), as they did not see themselves at risk and could not understand or accept why they suffered a cardiac event: "younger men are brought up to feel that they are a bit invincible, that you know, they're bullet proof and you know that doesn't happen to them" - Paul, as well as by older men who had previously recovered from severe illnesses such as a heart attack or a cancer and perceived themselves as warriors, "I survived a cancer before, I haven't much of a fear of dying"-Pat and 2) the sense of vulnerability expressed by men who described the cardiac event as a loss (of control, of power, of dignity, and of autonomy) or a fear (of receiving a life-treathening diagnosis, of permanent incapacity or disability, of early retirement, or of death). An additional explanation mentioned across groups was the competing priorities of daily living and putting others above self " it's hard to take time for yourself when you have a lot of obligations"- Marc. Stressing about the lack of time and being busy is used to positively

explain and justify the treatment-seeking delay behaviour. This type of avoidance behaviour in regards to seeking help was often perceived as being somewhat of a responsible and altruistic behaviour, thus making it more acceptable and meaningful and reinforcing the masculine gender role and its impact on engaging in help-seeking and treatment-seeking.

## "What am I doing here? What'd be my life once I'm back home?": The in-hospital journey

The hospital stay, whose length varied according to the severity of the cardiac event, was most often described as very difficult, involving sleepless nights, worries, fear of death, and sometimes anger. Having to "stay in bed" was depicted as a failure, a loss of power and confidence, or an unfair situation. "It changed my life totally. Like, you know, I was pretty confident, pretty, you know, I was a supervisor at my work, captain of my team, just, you know, that 10 feet tall and bulletproof. I wasn't there anymore, right?"- Jacques While reactions varied, one particular question transcended across groups: "what would be my life once at home?". The anxiety generated by this question was discussed in groups as an important concern.

Across groups, men typically shared that they were very satisfied with the care they received (i.e., procedures, medications, interactions with health professionals about their cardiac condition) during their hospital stay, but that one thing they tended to avoid discussing openly was their apprehension about life after hospitalization. Thus, uncertainty about life after hospitalization emerged as a dominant theme across groups when discussing in-hospital challenges. In-hospital uncertainty was further characterized by lack of, or inability to achieve, a clear understanding about the cardiac event, its impact on the body and daily functioning, eventual impact on one's job or employability, and risks in terms of survival (fear of death). The main reasons why men experienced anxiety in the form of uncertainty about the future were that they (a) did not understand, or accept, the cardiac event; (b) did not feel in control of their future (how things are going to evolve?); (c) were intimidated by unintelligible medical terminology and high-tech procedures; and (d) apprehended the adjustements and the changes to be implemented once at home. Uncertainty about the future was associated with lack of self-confidence and was exacerbated by poor health communication on the part of professionals and in some cases the patients themselves, who were often reticent to share their concerns or to ask questions. Communication behaviours on the part of health care providers such as speaking in general terms and referring to population statistics (as opposed to using more precise and personalized information), only communicating via short conversations in a shared room while patients are in bed (as opposed to creating opportunities for asking questions in a more confidential environment), or providing unclear explanations using medical jargon (as opposed to clear explanations in lay terms), appear to play a critical role in generating and exacerbating feelings of uncertainty and apprehension about the future.

#### "I'm not the man I used to be!": Post-hospital discharge

Returning home following a cardiac event was discussed as an important transitioning phase. Group discussions revealed that being told to "*slow down and stay home*," even for a short period, was often experienced as unacceptable and devaluing. Post-hospital discharge, especially in the early going, was associated with psychological distress, frustration, and discomfort related to adopting the recommended lifestyle changes (e.g., lower sodium intake, eating more fruits and vegetables, quitting smoking), resting at home, and daily medication intake. Lack of undertanding of medical advice and recommendations, lack of preparedness for the changes to be implemented, and the experience of having had a "brush with death" were mentioned as major stressors.

"You know, the thing that stuck in my mind the most, of this whole episode... I talked to the surgeon before the operation, and he went through all the steps of what's happening, and bottom line, there's a 2% chance that you're gonna die... That gets your attention"-Henry. "Like, this gentleman keeps saying "If it's your time to go, it's your time to go." But for me, I'm not saying that I'm more or less important, but I have a young kid, so when your doctor tells you that you better make sure that your will is fully done and your financial situation is good cause you're a ticking time bomb, at 40, I have a young kid and for me, it plays a lot in my head, right"-George. "What I found the hardest of all is before my operation and after, they told me what I could do, what I couldn't" -Virgile

Perceived control was identified as a dynamic cognitive process that fluctuated in response to the cardiac event. Men constantly attempted to retain or gain control during the rehabilitation phase and even beyond this period. Changes in environmental circumstances, such as being hospitalized for extended periods of time, re-hospitalization for complications and then being discharged home, impinged directly on their ability to feel in control of their daily lives. The process of gaining a better sense of control was facilitated by rationalizing, or making sense of a new phase in their treatment or illness prognosis or by gaining awareness of environmental challenges "once you accept that you are restricted in your physical abilities it gets easier"- Paul.

The post-hospital discharge and recovery process experience are mainly shaped by age, social connectedness (life partner, family, friends, and community involvement), psychological preparedness, personality, and economic status (finances, employment, etc.). Groups' narratives revealed that feelings of powerlessness and sleep disturbances were experienced at all stages of the rehabilitation process and were often associated with the fear of dying. *"I was afraid for a long time to go to sleep. I would stay up for like three days until somebody slept with me more or less, right? My girlfriend at the time, we didn't stay together every night, but if she wasn't with me, I wouldn't sleep. I was afraid to go to sleep and not wake up."*-**Albert**.

#### 3.2. Distancing, normalizing, and accepting

Men reported that stepping back and reflecting on their own emotional reactions and experiences helped them make sense of their changing lives post-cardiac event. Two

perpectives emerged : experiencing it as a personal failure and/or as an opportunity (a second chance for a better life). In both perspectives, they were ready to accept this new normality and were ready for adjustment. *"Once you accept that you are restricted in your physical abilities it gets easier"-Bernard.* They reported using various strategies (spirituality, religion, faith, praying, introspection, meditation) as means to help them make sense of their cardiac event and accept the situation *"Well, I wouldn't say I was completely free of worry for myself. Like the day before surgery, I went up to Sainte-Anne-De-Beaupré and I went to confession. So I was, you know. I wasn't completely fearless, going in"-Paul. "Well you know there's a lot of factors that impact on getting better support, prayer... I think prayer is a big thing, faith is a big thing too, you need to go for help"-Jack. "Spirituality helps, it gives you strengths and courage. I think it's a psychological thing"-Marc.* 

Increased awareness of one's mortality was described as a motivating factor to help them prioritize taking charge of their health. Redefining priorities with their life partner and family, or engaging in companionship was also described as helpful: "My wife as well was very helpful, which means, she was not entirely too sympathetic which is, this is what you need to do, you know (laughs)."-Patrick "Like she took care of all my meds. Prior to the surgery, she wouldn't even know what meds I was on. But after that, she was the one who knew what med, and when there were changes"- Albert.

After being stabilized medically, reactions varied among men. Groups discussed three main reactions: (a) processing and reflecting on the lived experience and engaging in adopting a healthy lifestyle as a personal or family challenge, (b) taking the necessary time to process the traumatic event (to absorb the shock and understand what was happening) and then gradually exploring options and implementing changes, and (c) resisting and ignoring recommendations, using self-reliance and continuing the same lifestyle as before the cardiac event. *"I disregarded anything that my doctors were telling me, and I said that I had to take control of my own situation."*-Charles

#### 3.3. Conformity to traditional masculine norms

Dominant masculine norms can affect perceptions, acceptance, and normalization of the psychological distress following a cardiac event as well as help-seeking behaviours and mental health services utilization. "Broken masculinity" emerged as a transversal theme illustrating how deeply "masculinity and virility" were affected following a cardiac event. The functional limitations (i.e. staying at home, not driving, not shovelling snow, not lifting heavy weights), prescribed by their doctor or that were consequences of their heart condition and related medication (i.e. erectile dysfunction), were experienced as a major loss of manhood "Well, weakness also. There's a role. You're the father, and there's a role. And there's responsibilities that go with that role. And you want to continue to do your job, as a father. And you don't want to show them that you're as vulnerable as you are at the moment. You kind of try to carry through. Which is tiring, cause then when they're gone, you're just wiped out. You just put everything. You put the whole day's energy into that session with them." – Jean-Pierre. Perceiving their social role as "family breadwinner" or "family strong pillar" prevented men from sharing their emotions and

worries to their children or relatives. The altruistic behaviours, such as protecting relatives from worries, are valued by men and are used as intrinsic strategies to regain self-confidence and sense of manhood. *"Well, I have a 14 year old son, who looks up to me I'm sure. I'm his father. So, you know, sometimes when I'd see him, surely, I'd say after the surgery when you're really not feeling yourself... You have to put on a game face because you really don't want to show exactly how you feel to your children, cause they're going to worry." - Brian.* 

The tendency to view and label certain behaviours as "feminine" as opposed to "masculine" seems to be an aggravating factor in terms of delaying or avoiding seeking help and using mental health services "...women will tend much more to talk about it to their friends in regards to how they're feeling. Where a man, sometimes it's hard to share with your partner sometimes. You don't want to show that sign of weakness, and that's the way that I look at it." – **Bill** "Suddenly you go through a heart attack and you will be like that (clic) the man they expect you to be, I mean the open minded... the touchy feel... you know... talking about private things... with people you don't know, Oh wow! Not me..."-Greg "I find that women will talk to each other about emotions and how they feel. But how often do you go to work and sit down with one of your friends and start talking about your emotional problems? Not often. It's just something that men don't do"-Alban

Men working in male-dominated workplaces (i.e., paramedics, police, military, construction, fishery industry) stressed the importance of educating people in their workplaces and of providing them with supportive tools and strategies. "*The other thing too is like, in the military, I was trained for 32 years to be macho. There's no such thing as being depressed or tired or... you know what I mean? You'd just go out and do your thing, that's just the way it was. And that training, today, is still instilled in me."*- Martin.

#### 3.4. Social, literacy, and communication challenges

Following a cardiac event, men felt they had to change certain patterns within their lives and adjust to changes in their role as life partners, parents, and employees. There was a perception of loss of confidence in their physical capabilities and functioning in family and work relationships. Low social connectedness and support before the cardiac event was discussed in groups as a risk factor for cardiac disease and mental illness and as associated with poor mental functioning and quality of life during the recovery period. The quality and the intensity of family relationships as well as those with friends and co-workers varied over the course of recovery post-cardiac event and were dependant on men's acceptance of the situation and their need for help. When discussing social support and its relevance for a healthy recovery, the necessary balance between expected and received support emerged as key. Indeed, while they found it sometimes difficult to share their thoughts and challenges with their relatives, men appreciated the attention, the compassion, the understanding, and the support of their life partner, family members, and friends. Supportive interpersonal relationships were viewed as helpful for breaking the cycle of distress and anxiety. The support received improved men's trust in their ability to deal with the cardiac event, the cardiac rehabilitation, and the necessary

adjustments. However, men mentioned sometimes being irritated because of the overprotectiveness of some relatives. In particular, being under 'spouse's management', they felt that they had lost part of their personal space, their independence and manhood. "...All of a sudden, people feel, my wife in particular, well, here's somebody who's not an invalid, but we have to, you know, every time you do anything it's well, you shouldn't be doing this, you shouldn't be doing that, you shouldn't be... And that sort of affected me – it still does – more than any other things..." – Mark.

Sexual problems developed in the aftermath of the cardiac event, either functional ones related to their ability to sustain an erection or to ejaculate (often side-effects of medications), or psychological ones that involved fears of exacerbating their heart condition if they were to engage in sexual activity, were described as a major concern. "Sexually, I'm not the man I used to be. It's just – and I blame it on the pills – it's just that my life has changed drastically...I keep toying with the idea that maybe I should stop taking the pills, but I know that it's gonna get me one way or the other... So... it's really finding a sweet spot with the right medication."-Wayne "you don't have anymore the sexual drive, you know, that you had before"-Martin

#### **Concerns about work**

As work is a significant aspect of personal and social identity, being on a long term sick leave may lead to feelings of shame and guilt or regarding oneself as incompetent, incapable, or physically weak. "I've been out of work for a year and a half. I don't want to go back there. I don't want the stress of it. In the meantime, my work's moving, so we're all going to lose our jobs anyways. I've been there 22 years. So it's just another stressor, right? And a lot of stuff outside of work, and it's a helpless feeling."-Paul. "I supervised the Giant Tiger warehouse. I couldn't do that anymore. You know what I mean? Stuff like that, you know? The only thing I do anymore is play baseball. That's just it..."-Richard. Early returning to work, even againt medical advice, is discussed as a problem-solving strategy to reinforce self-confidence and overcome stress. "The cardiologist came, he says, "well, we have to do a triple bypass". I looked at him, I said, "well, how long am gonna have to stay in the hospital?". He said, "two weeks". I says, "I don't have time for that. I have to be back at work for the 29th"-Serge "after my heart attack, the only thing I wanted to do was get better so I could go back to work, 'cause I'm only 52 and I need to work. So, that's all about"-Georges

#### Health literacy, health communication and health services navigation

Men's health literacy was pointed out as a major challenge. The lack of understanding medical jargon and procedures emerged as an additional stressor and was described as a barrier for asking questions and seeking more information, explanations, or advice. The bidirectional association between cardiac health and mental health was unclear and not fully understood. Moreover, mental illness signs, symptoms, and diagnostic labels seem to interfere with the masculine ideals. Indeed, men did not identify themselves as "depressed", "stressed", or "anxious" but used restrictive vocabulary to express emotional distress like "low energy", "challenged", or "meeting temporary difficulties".

Men valued the quality and human kindness associated with healthcare providers they had access to and described how the interactions, the conversations, and the alliance they had with them enhanced their compliance with treatment plans and improved their general mental and physical health status. "…*They gave me all the paperwork, all the stress things, charts and stuff, and my GP was great. She would ask me how my mental state was. I don't know guys like that. I appreciate it, but my doctors know her when I go in her office. She's in no hurry. If I'm sitting there crying for 15 minutes, she's there for 20 with me. So, yeah, I'm very lucky. I have great doctors…"- Serge* 

Men put a strong emphasis on the quality of communication they had with health professionals, such as being listened to, not being rushed, receiving care with sympathetic attitude, being trusted and taken seriously "I feel comfort. I feel comforted going to them. I really get a sense from my doctors that they really care about me."-William.

However, the lack of time allocated by physicians to address emotional distress and social challenges following a cardiac event was reported as a barrier for access to supportive and caring services: "You look at the doctor as being event-centered. In other words, he's there for a medical purpose. You have your 10 or your 15 minutes, and you're gone. You know, we're talking today about emotions, and this seems to be a time-consuming expensive exercise that at least the professionals I've dealt with haven't been available for. And you feel as though you're intruding on their importance, I guess, by, you know, having long chats and that sort of thing."-Patrick. Men felt pressured by time: "I just felt like I was just in and out like I was at a hair salon or something. You know, get this done, get the ECG done, and okay, see you later. Here's a prescription... I always felt like I was being rushed and brushed off. And so there was no relationship"-Mike. "You know, you've got your so many minutes. And I still think in our health system – and maybe not what's in the future – but if there was some minor pay for service, I think that would be helpful because you always feel you're on a sort of a diet of service. You're in; you're out, and of necessity. They move on to the next person."-Bruce.

The lack of knowledge about the health system and how to navigate services and manage medical information appeared to lead to the perception of the healthcare system as a "men-unfriendly space" where they feel discomfort and uncertainty: "I think there's a problem with men as a whole, and you know, women seem so much more in tune with, you know, going to see the doctor for themselves, child birth, kids, I mean, when my son was ill, I never went to the doctor with him, my wife took him and it just wasn't a place I'd go; didn't know him very well, didn't know much about what to tell him"-Philip. Moreover, the perceived conflicting information received from different health professionals increased anxiety and stress about how to manange health conditions and how to use health services. Men participating in cardiac rehabilitation programs reported the benefits of social interaction with other cardiac patients, identified as the "cardiac family". Sharing a similar health condition helps to normalize the challenges and accepting the "new reality".

#### 4. Discussion

This study aimed to describe the emotional issues and understand the patterns of psychosocial adjustment experienced by men following a cardiac event. Across the three Canadians provinces, participants showed homogeneity in reported experiences of the cardiac event, and its subsequent psychological reaction and social impact. Adaptation to the event, both psychologically and socially, did not appear to relate to geographical location but rather to intra-individual experiences and differences (ie., cultural norms, beliefs, relationships, etc.)... In the focus groups men opened up readily about their emotions and their vulnerabilities. They shared their experiences and difficulties in adapting and adjusting to their "new post-cardiac identity" as well as the need to accept new roles. They acknowledged that this adjustment needed to be worked out with their environment, their home, their family, their friends, and their workplace. Most often they found support through their partners and through peer support when they attended cardiac rehabilitation sessions. The focus group sessions helped to validate and normalize their initial reactions. They regretted that the health professionals they had encountered had not enquired in a systematic way about their mental well-being as they would about their physical symptoms or diet or exercice. This is certainly on aspect of practice that would be pertinent for health professionals to change.

One important overarching element that was brought forth by men was the lack of systematic attention given by healthcare professionals to the psychological consequences of having experienced a cardiac event. It was suggested that some professionals may bring up the subject, but in most instances, the question was not asked. Therefore, there seems to be a lack of consistency within the health system in regards to the attention paid to the psychological sequelae of heart disease. These aspects were reported in previous studies on various health conditions [18–20]. However, there is still a lack of clear and evidence-based guidelines and resources to support men-sensitive health communication as well as clinical practices to foster men's mental health. This study also revealed how traditional masculine norms can affect the way men experience and seek help for emotional distress following a cardiac event, and how these behaviours affect their health and wellbeing. Tailoring and targeting clinical interventions may increase men's service uptake and the efficacy of treatments. Specific factors associated with men's access to, and engagement with mental health care are critical to increasing help-seeking, treatment uptake, and effectual self-management among men experiencing emotional distress following a cardiac event.

While the literature contains extensive reports on "toxic masculinity" as a major determinant of men's health [21] or its impact on help-seeking in men [22], our study revealed "broken masculinity" to be an untold and unrecognized distress following a cardiac event. We found that men experienced a great deal of psychological anguish over the changes imposed by their cardiac illness, and that these changes were directly related to their sense of themselves as men in their family and in society. Our results confirm, as suggested by previous research, that it will be crucial to address these
concerns in a systematic way in order to combat symptoms of depression, anxiety, and post-traumatic stress in men following a cardiac event [23,24].

Our results corroborate and extend what other researchers have found concerning the psychological impact of a cardiac event. The sense of uncertainty, stress, discouragement, and sometimes hopelessness that many men in our sample talked about as they struggled to come to terms with heart disease and its effects on their personal and professional lives is consistent with the elevated levels of depression, anxiety, and post-traumatic stress reported among men (and women) elsewhere in the literature [1,2]. This sense of "broken masculinity" might be dangerous because it reflects, among other things, an espousal of attitudes and values that emphasize self-sufficiency and strength to such a degree that men refrain from addressing concerns related to their physical and mental health. Indeed, the results of previous studies [8,10] have indicated that traditional attitudes of this nature are related to poorer health outcomes in men than in women.

The lack of readily accessible and understandable information on the mental health aspects of heart disease that we noted in this study, along with the emotional, professional, and interpersonal challenges that men discussed, suggest that healthcare providers need to be better informed not only of the psychological consequences of heart disease but also of gender-specific ways of coping with them. Although there are examples of some initiatives that move in this direction (e.g., the Canadian Rehabilitation Network of Ontario, the Atlantic Cardiac Rehabilitation Network), to our knowledge there is not yet a comprehensive strategy for addressing themes like "broken masculinity" in male cardiac patients. For this reason, it is imperative to develop and implement interventions that will take into account the psychological impact of heart disease on men's sense of self, their relationships, and their work, along with the importance of adopting more flexible attitudes about what it means to be a man (i.e., a strong man asks for help when he needs it; a strong man takes care of himself and of others).

#### Limitations

The participants in this study were mostly in their sixties and over, which is representative of the population of men with cardiac disease. However, it would be of interest to study more specifically cardiac disease in men in their 30s, 40s, or 50s as cardiac disease is becoming more prevalent in these men.

The participants in our study were essentially white, with little or no representation of other ethnic groups or indigenous people. This may not be representative of larger urban Canadian settings.

Although our inclusion criteria indicated a cardiac event in the last 5 years, for some participants, the first event may have occurred some 10 years prior and there may have been changes in cardiac rehabilitation programs and health services. Moreover, the

responsiveness of health professionals at the time may have been different. A quantitative study exploring these aspects may allow to retrieve accurate information.

#### Strengths

This study is the first of its kind to delve into the subjective experience of men with heart disease and to examine the link between their reactions to their cardiac event and their mental health. We were able to detect key themes that are likely to resonate with most men who have heart disease, which could serve as a foundation for the development of intervention programs, i.e. the stepped-care model.

#### 5. Conclusion

This paper highlights the significant emotions that arise following a cardiac event and how men attempt to counter them as best as they can. It is known that men have a tendency not to talk about their emotions or to express them differently than women do. Health professionals caring for men in these contexts must be aware of this and receive training in gender-sensitive approaches. It will be important to systematically inform their patients of the possible occurrence of such emotions as well as the tools and ressources to self-manage as a first step. Considering the impact on morbidity and mortality when anxiety, depression, or post-traumatic stress are in the diagnostic picture, cardiologists, cardiac surgeons and family physicians as well as psychologists and other health professionals involved in cardiac rehabilitation programs must be ready to systematically inquire and to screen their patients for common mental health conditions. Improved mental health of these patients will most likely improve their cardiac disease. A larger study is underway to longitudinally investigate the need for emotional support among men following a cardiac event as well as exploring acceptability and feasibility of mensensitive stepped-care models.

**Ethical approval** The study received ethical approval from the research ethics boards (REB) of the participating study sites: Réseau de santé horizon : 2016-2295; Réseau de santé Vitalité : 2016-04-13; Université de Moncton : 1516-047; Hôpital Montfort : JJ-04-11-15; Institut de cardiologie de l'Université d'Ottawa : 2014-1801 (#projet), formulaire F11-4318; Université de Montréal : MP-33-2016-2006 (# projet), demande # F0-7529; and Hôpital de Hull : 2016-159 (# projet). All participants signed a confidentiality and consent form.

Acknowledgements The authors would like to thank the staff of the participating cardiac rehabilitation programs for their support with men recruitment, and the research staff (Arielle Doiron, Lise Gallant, Sarah Nowlan, Vanessa Tassé and Mireille Ntambwe) for their contribution in the transcription of verbatims, the data organization and the preliminary coding. The authors would also like to thank the men who have contributed to the focus groups and semi-structured interviews.

**Funding** This paper represents independent research, for which authors received funding from the Movember Foundation-Canada and from the New Brunswick Health Research Foundation. JJ would also like to acknowledge the logistic and financial support provided by the Centre de formation médicale du Nouveau-Brunswick to support this publication.

Competing interests None declared.

**Contributorship statement** All authors (Jalila Jbilou, Jean Grenier, Marie-Hélène Chominenne, France Talbot, Heather Tullock, Bianca D'Atono and Paul S. Greenman) have contributed significantly to the design of the project, the planning and the conduct of the data collection, they participated to the team work for the analysis of the data (development of the codebook, training of the research assistants (for first coding and codes' organization), discussions if consensus was not achieved and worked collaboratively on 2<sup>nd</sup> coding and conceptual categorization) and the discussion of the results. Jalila Jbilou and Jean Grenier prepared the first manuscript draft; all authors contributed to, review and approve the final manuscript.

**Data sharing statement** All transcripts have been de-identified following ethical recommendations to protect participants' privacy and confidentiality. Unfortunately, we do not have consent from participants to share the full denominated data publicly. However, Codebooks or sections of the transcripts can be requested by contacting the corresponding author.

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#### **APPENDIX 1**

#### « MIND THE HEART » PROJECT

#### FOCUS GROUP DISCUSSION GUIDE

#### **ENGLISH VERSION**

#### INTRODUCTION

Thank you for agreeing to participate in this focus group discussion. This discussion is part of a multi-site participatory action research project, « MindTheHeart », funded by Movember Foundation Canada and the New Brunswick Health Research Foundation that aims at raising awareness for psychologically healthy workplaces for men living with or at risk of HD.

The purpose of this focus group is for the research team to understand the needs, expectations and preferences of men at risk of or living with HD, with regard to interventions such as mental health promotion, mental health prevention, and mental health interventions for MD/AD/TRD. The information gathered will help the research team to design interventions that meet the specific needs of men with HD to prevent or early detect and treat co-occurring mental health issues.

Before we start the discussion, allow us to clarify some points.

1. Could you all kindly verify that you have already signed the consent forms stating your voluntary participation in this focus group?

Yes 🗆

No 🗆

- 2. The duration of the focus group discussion will take 90 to 120 minutes in which you have the right to leave the group at any point in time.
- 3. The whole session will be audio recorded to ensure the accuracy of the information that you provide. However the consent forms that you have signed will ensure that all the information that you share today shall be confidential and anonymous.
- 4. Please note that each of you confirms that you are aware that anything said during the meeting has to be kept confidential and that you understand that you are not allowed to disclose any information or any names related to this focus group.

Would anyone like to ask any question or has any clarification related to this focus group before we start?

Before we start, could you please take a few minutes to complete this general information sheet? (Give them the information sheet below)

For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

2

#### BMJ Open

The objective of the following form is to collect general information about you. You can be assured that the information collected will remain confidential and anonymous.

3 4	1-	Age
5 6	2-	City of residence
7 8 9 10 11 12 13 14 15 16	3-	Familial status (tick as apply).          Single (never married)         Married         Common law partner         Divorced         Widow         Other (specify):
17 18 19 20 21 22 23 24	4-	Level of education: (tick as apply). Not schooled Primary Secondary College University Other (specify):
26 27 28 29 30	5-	Employment status: (tick as apply) Employed Retired Sick leave
31 32 33 34 35 36 37	6-	Preferred language for health services (tick all that applies). French English Others (specify):
38 39 40 41 42 43 44 45 46 47 48	7-	What is your ethnicity? (tick all that applies). White/Caucasien Black (ex., Haitian, African, Jamaican, Somalia) Latino/Hispanic Asiatic (ex., Chinese, Japanese, Vietnamese) Middle East Native/First Nation/Mixed-Race Pacific Island Other (specify):
49	<u>Health</u>	status
51 52 53 54	1-	Are you suffering from, have you ever suffered from or are you at risk of heart disease? (if yes, please specify)
55 56 57 58	2-	Are you suffering from a mental health issue? (if yes, please specify)
59 60		For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

#### BMJ Open

### FOCUS GROUP DISCUSSION GUIDE

## 1 **A. Patient Experience**

<b>B. He</b> What d	Physical well-being (performing your daily activities, energy levels and physical activity) Emotional well-being (interest in sex, experienced feelings, mood and relationships with others) Mental health issues (mood and anxiety, ability to make 'good' decisions and be productive) Financial situation Employment situation (absence from work, productivity, demotions, arguments with colleagues and superviso stigma, loss (advantages, respect, confidence)) For many men, self-reliance and being competitive are important characteristics. How about you? What a important manly characteristics for you? How might that have changed with HD and mental health issues? How do you deal with those changes? Ealth Promotion and Prevention Needs to you know about the link between HD and mental health issues in men? Health literacy/Knowledge/Health education
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What d	lo you know about the link between HD and mental health issues in men? Health literacy/Knowledge/Health education
- - -	Health literacy/Knowledge/Health education
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-	What do you wish you had known or done that might have helped you avoid HD and mental health issues?
-	For other men experiencing HD and mental health issues, what are the most important pieces of information ab
р .	the link between HD and mental health issues and how might they be best convoyed?
100000	the mix between first and mental health issues. What kind of information shout montal health and UD do
Regard	
think w	/ill be most useful for you?
-	Type of information (statistics, recommendations, health advice, explanations)
-	Communication channels: (read, audio or visual media, seminars, peer education, educational materials, oth
	specify)
-	Location of information delivery (workplace, health care services, community, media)
-	Timeliness of information delivery (moment/delay)
-	Websites, apps, social media, men testimonies as a source of information, interest and use
What is ast fiv	s your experience with the health care that you were provided due to your HD and mental health issues needs in e years?
_	How connected are you to the health care system and specialist heart and mental health services?
_	Relevance of care: Many men tell us they don't want to rely on medications to ensure their mental health or the
	specific ailments such as depression? What is your perspective/experience? What is your advice to health c
	providers about working with male nations who have experienced HD and/or mental health issue?
	Utilization of services: Lots of men are raticent to use professional mental health services why might that
-	What shout you, what shallon good did you have in cooking heart on monthly health core?
	what about you, what chanenges did you have in seeking heart of mental hearth care?
-	Availability and access to care? (existence of men-sensitive services, factors related to utilization of services)
	psychologist, insurance coverage, social services)
-	What were some of the areas that you suggest be improved? (your expectations)
Could	you please describe your experience with your health care professional (family doctor, cardiologist, nutrition
kinesio	logist, social worker, psychologist, and counselor) regarding information about mental health issues and h
disease	??
-	Information/Education provided: What type of patient are you? One who likes to be told what to do or would
	rather be more involved in the decision making and strategies? Please provide an example of that round your
	and/or mental health issues?
_	Perceived expectations and needs
	Patient/Clinicians dynamics (communication relationship openness empathy and shared decision making)
	Proposed improvements: Can you provide an example of a positive interaction/relationship with a specific ba
-	are professional? What are the abarratoristics of a prost health care professional?
	care professional? what are the characteristics of a great health care professional?
-	How does the gender of the health care professional influence that relationship?
-	Some men like to lead – others like clear instructions. What is your preference and experience of interacting v
-	health care professional?
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# Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

#### Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

## YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	All authors conducted the focus group or the semi-structured interview	Method- Page4
2. Credentials	JJ PhD, MD JG PhD, CPsych MHC MSc, MD FT PhD, LPsych HT CPsych BD'A PhD PSG PhD, CPsych	Title page-1
3. Occupation	What was their occupation at the time of the study? Researchers, Clinicians or both.	-
4. Gender	Was the researcher male or female? Males (JG, PSG) and Females (JJ, MHC, FT, HT, BD'A)	-
5. Experience and training	What experience or training did the researcher have? A MindTheHeart manual for the qualitative study was developed. Training was offered to the researchers and the research staff involved in this study.	Methods-Page 5
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement? No	-
7. Participant knowledge of the interviewer	What did the participants know about the researcher? Ethical approval had been granted from REB in all participating sites.	Ethical approval- Page 15-16
	information sheet and had the opportunity to ask their questions to the interviewers prior to giving their written informed consent.	Method-Page4

8. Interviewer	What characteristics were reported about	-
characteristics	the inter viewer/facilitator? e.g. Bias,	
	research topic	
	No interviewer-related bias was identified.	
Domain 2: study design		
Theoretical framework		
9. Methodological	What methodological orientation was	Methods-Page 5
orientation and Theory	stated to underpin the study? e.g.	
	ethnography, phenomenology, content	
	analysis	
	Open and axial coding with interpretative	
	phenomenological analysis.	
Participant selection		
10. Sampling	How were participants selected? e.g.	Methods-Page 4
	purposive, convenience, consecutive,	
	Convenience samples	
	The inclusion criteria were: 1) to be 19 and	
	over in New-Brunswick, and 18 and over in	
	Ontario and Quebec; 2) to have had a	
	myocardial infarction, unstable angina, or	
	heart surgery in the last 5 years with or	
	be able to read and speak English or	
	French: and 4) to be willing to participate in	
	a group discussion.	
11. Method of approach	How were participants approached? e.g.	Methods-Page 4
	face-to-face, telephone, mail, email	
	To recruit participants we used a combination of active strategies (natients'	
	solicitation at participating cardiac	
	rehabilitation programs and a snowball	
	technique) and passive strategies (radio	
	broadcasts and local newspapers	
	advertisement).	
12. Sample size	How many participants were in the study?	Results-Page 5
13 Non participation	93 men How many people refused to participate or	
	dropped out? Reasons?	-
Setting		
14. Setting of data	Where was the data collected? e.g. home,	Methods-Page 4
collection	clinic, workplace	
45 D	At the University or the hospital	
15. Presence of non-	vvas anyone else present besides the	-
16 Description of sample	What are the important characteristics of	Results-Page 6
	the sample? e.g. demographic data. date	
	Data presented in a Table (Table 1)	

Data collection		
17. Interview guide	Were questions, prompts, guides provided	
	by the authors? Yes	Appendix1 Guide
	Was it pilot tested? The guide was	Method-Page 4
	reviewed by four patients who did not	
18 Repeat interviews	Were repeat inter views carried out? If yes	
10. Repeat interviews	how many? No	
19. Audio/visual recording	Did the research use audio or visual	Methods-Page 4
	recording to collect the data? Audio	
20. Field notes	Were field notes made during and/or after	Methods-Page 5
	the inter view or focus group? Yes	
21. Duration	What was the duration of the inter views or	Results-Page 5
	focus group? Each focus group consisted	
	approximately two bours $(+/-35 \text{ minutes})$	
	The semi-structured interview lasted	
	between 60 and 90 minutes.	
22. Data saturation	Was data saturation discussed?	Methods-Page 4
23. Transcripts returned	Were transcripts returned to participants	-
	for comment and/or correction? No	
Domain 3: analysis and		
findings		
24 Number of data coders	How many data coders coded the data? 12	Methods-Page 5
	coders	Methods-Fage 3
25. Description of the	Did authors provide a description of the	-
coding tree	coding tree? No	
26. Derivation of themes	Were themes identified in advance or	Methods-Page 5
	derived from the data? Derived from the	
	data	
27. Software	What software, if applicable, was used to	NVivo 11 Pro
29 Darticipant checking	Did participanta provide feedback on the	Strongthe and
	findings? Yes	limitations
Reporting		
29. Quotations presented	Were participant quotations presented to	Results
	illustrate the themes/findings? Was each	
	quotation identified? e.g. participant	
	number Yes	
30. Data and findings	Was there consistency between the data	Discussion
CONSISTENT	presented and the findings? Yes, mainly	Doculto
	the findings? Yes	Results
32. Clarity of minor themes	Is there a description of diverse cases or	Discussion
	discussion of minor themes? Yes	
		1